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ABSTRACT

A Senate hearing reviewing health care services available for people with Alzheimer's disease and related dementia and reviewing proposals related to the treatment of Alzheimer's disease is presented in this document. Statements are given by Senators Charles E. Grassley, Albert Gore, Paula Hawkins, Howard M. Metzenbaum, Larry Pressler, and Paul Simon. Witnesses testifying or providing statements include: (1) American Association of Homes for the Aging; (2) Robert Cook-Deegan, Senior Analyst and Project Director, Office of Technology Assessment, United States Congress; (3) Peter J. Whitehouse, director, division of behavioral neurology, Case Western Reserve University; (4) Kathleen C. Buckwalter, associate professor, College of Nursing, University of Iowa; (5) Robert B. Helms, Assistant Secretary for Planning and Evaluation, Department of Health and Human Services; (6) Gene D. Cohen, director, Program on Aging, National Institute on Mental Health and executive secretary, Task Force on Alzheimer's disease, Department of Health and Human Services; (7) Jerome H. Stone, president, Alzheimer's Disease and Related Disorders Association; (8) Lisa Gwyther, director, Alzheimer's Family Support Program, Duke University Aging Center; and (9) Janet Sainer, commissioner, New York City Department for the Aging. Witnesses' responses to Senators' questions are included. (ABL)

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S. Hrg. 99-913

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

ED290098

HEARING

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

NINETY-NINTH CONGRESS

SECOND SESSION

ON

REVIEW OF HEALTH CARE SERVICES AVAILABLE FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIA AND TO REVIEW PROPOSALS RELATED TO THE TREATMENT OF ALZHEIMER'S DISEASE

JULY 22, 1986

CG 020461

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ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

TUESDAY, JULY 22, 1986

U.S. SENATE,
SUBCOMMITTEE ON AGING,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The subcommittee convened, pursuant to notice, at 9:40 a.m., in room SD-430, Dirksen Senate Office Building, Senators Pressler and Charles E. Grassley (chairman of the subcommittee) presiding.

Present: Senators Grassley, Metzenbaum, and Hawkins.

Also present: Senators Pressler and Gore.

OPENING STATEMENT OF SENATOR GRASSLEY

Senator GRASSLEY. I will call this meeting of the Subcommittee on Aging of the Senate Committee on Labor and Human Resources to order.

I want to explain my 10-minute delay. I was just involved in the opening of the Subcommittee on Trade, and I may call a recess of this hearing about 10:30, so I can go back and ask about 10 minutes of questions. I just make that announcement so anybody in the audience who is not used to the schedule of the Congress will understand that.

I am going to insert my statement in the record and ask Senator Metzenbaum if he has an opening statement, and then I will call on my colleagues, who have been very faithful in waiting.

[Senator Grassley's statement follows:].

United States Senate

COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510

STATEMENT OF SENATOR CHUCK GRASSLEY BEFORE THE SUBCOMMITTEE ON AGING OF THE SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES FOR A HEARING ENTITLED "THE CARE OF PEOPLE WITH ALZHEIMER'S DISEASE", JULY 22, 1986.

GOOD MORNING. PLEASE COME TO ORDER. I AM CHUCK GRASSLEY, CHAIRMAN OF THE SUBCOMMITTEE ON AGING. WELCOME TO THIS HEARING ON THE SUBJECT OF CARING FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS.

THIS HEARING IS ONE OF A SERIES OF MEETINGS THIS SUBCOMMITTEE HAS HAD ON ALZHEIMER'S DISEASE DURING THIS AND THE LAST CONGRESS. OUR FIRST HEARING ON THIS SUBJECT, ONE OF THE FIRST IN THE CONGRESS, IN JUNE OF 1983, FEATURED TESTIMONY BY MARGARET HECKLER, THEN SECRETARY OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. IN WHAT WAS HER FIRST APPEARANCE BEFORE CONGRESS SHE DISCUSSED PROGRESS IN BIOMEDICAL RESEARCH INTO THE CAUSES OF ALZHEIMER'S DISEASE AND ANNOUNCED THAT SHE WAS MAKING WORK ON ALZHEIMER'S DISEASE ONE OF THE DEPARTMENT'S HIGHEST PRIORITIES.

IT IS CERTAINLY APPROPRIATE THAT A HIGH PRIORITY BE PLACED ON MAKING PROGRESS AGAINST ALZHEIMER'S BECAUSE THIS DISEASE MUST BE ONE OF THE MOST DEVASTATING KNOWN TO MAN. ALTHOUGH INDIVIDUALS AFFLICTED WITH IT MAY REMAIN IN RELATIVELY GOOD PHYSICAL HEALTH FOR A RELATIVELY LONG PERIOD OF TIME, THEY INEVITABLY EXPERIENCE PROGRESSIVE AND VERY DESTRUCTIVE MENTAL DETERIORATION. THE BEHAVIOR ASSOCIATED WITH THIS MENTAL DETERIORATION MAKES CARING FOR ALZHEIMER'S VICTIMS EXTRAORDINARILY DIFFICULT.

FURTHERMORE, ALTHOUGH PRIMARY RESPONSIBILITY FOR THE CARE OF ALZHEIMER'S VICTIMS HAS FALLEN ON FAMILIES, THIS DISEASE IS ALSO AN ENORMOUS NATIONAL AND PUBLIC BURDEN. BEST ESTIMATES INDICATE THAT BETWEEN TWO AND THREE MILLION AMERICANS PRESENTLY HAVE ALZHEIMER'S DISEASE OR A RELATED DEMENTIA. STUDIES HAVE ESTIMATED THAT HALF TO TWO-THIRDS OF NURSING HOME PATIENTS HAVE DEMENTIA. THE TOTAL DIRECT COSTS OF CARING FOR THOSE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS IS ENORMOUS; CONSERVATIVE ESTIMATES RANGE BETWEEN $38 BILLION AND $42 BILLION PER YEAR FOR DIRECT COSTS ALONE.

SINCE MRS. HECKLER'S APPEARANCE BEFORE THIS SUBCOMMITTEE, A BIOMEDICAL RESEARCH EFFORT HAS BEEN COMMENCED AT THE NATIONAL INSTITUTE ON AGING AND, ACCORDING TO ALL REPORTS, HAS BROUGHT A NEW LEVEL OF EXCITEMENT AND ENERGY TO BIOMEDICAL WORK IN THIS

FIELD. CERTAINLY, EMPHASIS ON THE BIOMEDICAL RESEARCH PROGRAM MUST CONTINUE. MOST OF US PROBABLY FEEL THAT IT IS IN THIS AREA THAT AN EVENTUAL SOLUTION TO THIS PROBLEM RESTS.

UNFORTUNATELY, HOWEVER, THERE IS LITTLE LIKLIHOOD OF AN IMMEDIATE BIOMEDICAL BREAKTHROUGH WHICH WOULD ELIMINATE OR EVEN SUBSTANTIALLY REDUCE THE NUMBER OF DEMENTIA VICTIMS OR THE DIFFICULTIES OF CARING FOR THEM.

THEREFORE, WE WILL CONTINUE TO BE FACED WITH THE ENORMOUS BURDEN OF CARE WHICH WILL BE REQUIRED BY THIS LARGE GROUP OF PEOPLE.

UNFORTUNATELY ALSO, OUR ADVANCE IN THIS REALM HAS BEEN IMPEDED BY THE FACT THAT THE PROGRESS REFLECTED IN THE BIOMEDICAL RESEARCH AREA HAS NOT BEEN REFLECTED IN RESEARCH DEVOTED TO UNDERSTANDING THIS POPULATION OR HOW BEST TO CARE FOR THEM.

AS A FIRST STEP TOWARD BETTER UNDERSTANDING OUR NEED IN THIS AREA, THIS SUBCOMMITTEE HELD A WORKSHOP ON SERVICES-RELEVANT RESEARCH ON ALZHEIMER'S DISEASE. THIS WORKSHOP WAS JOINTLY SPONSORED BY THIS SUBCOMMITTEE, THE SUBCOMMITTEE ON HUMAN SERVICES OF THE HOUSE SELECT COMMITTEE ON AGING THROUGH THE EFFORTS OF OLYMPIA SNOWE, THE RANKING MINORITY MEMBER, THE OFFICE OF TECHNOLOGY ASSESSMENT, AND THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION. SEVERAL OTHER MEMBERS OF THE SENATE AND THE HOUSE OF REPRESENTATIVES ALSO SPONSORED THE WORKSHOP.

WHAT EMERGED CLEARLY FROM THAT WORKSHOP IS THAT MORE ATTENTION NEEDS TO BE GIVEN TO SERVICES-RELEVANT RESEARCH ON THIS POPULATION, TO EDUCATION AND TRAINING OF ALL THOSE WHO MUST WORK WITH ALZHEIMER'S DISEASE AND OTHER DEMENTIA VICTIMS, AND TO IMPROVING THE CIRCULATION OF ACCURATE INFORMATION ON AVAILABLE PROGRAMS FOR VICTIMS AND THEIR FAMILIES.

TODAY, WE WILL HEAR FROM SEVERAL KNOWLEDGEABLE WITNESSES ABOUT A NUMBER OF BILLS WHICH HAVE BEEN REFERRED TO THIS SUBCOMMITTEE AND WHICH, IN THEIR DIFFERENT WAYS, ADDRESS SOME OF THE NEEDS TO WHICH I JUST REFERRED.

WE ASKED OUR WITNESSES TO DO TWO THINGS: FIRST, TO PROVIDE SOME BACKGROUND FROM THEIR RESPECTIVE VANTAGEPOINTS ABOUT SERVICES AND SERVICES-RELEVANT RESEARCH AND TRAINING, AND, SECOND, TO COMMENT ON THE VARIOUS BILLS WHICH HAVE BEEN REFERRED TO THE SUBCOMMITTEE. GIVEN THAT EACH WITNESS HAS A LIMITED AMOUNT OF TIME, WE ANTICIPATE THAT COMMENTARY ON THE BILLS WILL BE

SELECTIVE AND WILL FOCUS ON THE BASIC IDEAS EMBODIED IN THE BILLS.

I THINK THAT OUR PERSPECTIVE ON THESE BILLS WILL BE GREATLY ENHANCED BY THE TESTIMONY WE RECEIVE TODAY AND THAT THE SUBCOMMITTEE WILL BE IN A BETTER POSITION TO MOVE FORWARD WITH LEGISLATION IN THIS AREA.

WITH THAT, LET US TURN TO THE FIRST PANEL.

Senator GRASSLEY. Senator Metzenbaum.

Senator METZENBAUM. Thank you, Mr. Chairman.

I want to thank you for holding this hearing on Alzheimer's disease and related disorders. I have no doubt that many millions of Americans thank you as well.

The Alzheimer epidemic is a real and present threat to the health of our citizens. It is a devastating illness and yet 25 years ago, probably even 10 years ago, nobody would have been talking about Alzheimer's disease. And all of a sudden, it pervades the entire community and all aging persons thinks about whether or not they may or may not have become victims of Alzheimer's.

Unless we act soon, the graying of America could prove devastating to our resources, our health care providers and institutions, and most of all, to our families. By the year 2030, the number of older citizens will almost double to 21 percent of the total population. That means one out of every five people in the community will be an older person.

Half of these will be over 75, the seniors most vulnerable to Alzheimer's disease. The over-65 years are supposed to be the golden years, but more and more elderly will find that those years are grim, hopeless struggles for survival.

Unless we commit adequate resources now to prevent the tragedy of dementia, Alzheimer's disease could well bankrupt the Nation physically, emotionally, and financially.

I have personally known many competent, productive people who have been victims of this dread disease. I had one friend who played tennis; he could play tennis well, but he could not remember how to get to the tennis court.

I have two friends whose husbands, contemporaries of mine, both succumbed to the dread illness, Alzheimer's.

The first employee that I had in my company, his wife has had Alzheimer's for many years. And I cannot call the home of my good friend and talk to him without hearing his wife in the background, crying out with her pleas and cries of anguish.

A good friend, Jerome Stone, whose lovely wife was a victim for many years, is here today as a witness. Jerry is the founding president of the Alzheimer's Disease and Related Disorders Association. He is here to testify to the dedication, the burdens, and the needs of hundreds of thousands of families who are now caring for their demented loved ones.

Sadly, one of the afflicted families is that of my friend and colleague, the distinguished Senator from South Dakota Larry Pressler, who is here today as a witness.

Wherever you turn, rich or poor, black or white, rural or city dweller, Alzheimer's has no limit. This is a cruel disease that robs victims of memory, of personhood, of dignity and of lifetime savings, too. Not only 2.5 million victims, but the families who care and watch also suffer immeasurably.

I introduced legislation several years ago to expand research, to provide some financial relief to family caregivers, to urge the Veterans' Administration to develop a consistent policy regarding Alzheimer's victims. In this Congress, I introduced S. 1835 and S. 2183, which would provide a comprehensive approach to the problem of Alzheimer's disease and related disorders.

S. 2183, a bill before the panel today, is similar to the more comprehensive S. 1835, which was referred to the Committee on Finance. The original S. 1835 included additional provisions dealing with tax policy, Medicare, small business loans for nonprofit adult daycare, Veterans' Administration programs, and a National Council on Alzheimer's Disease.

While I continue to believe that the original bill, S. 1835 should be enacted to assure a comprehensive Federal program on Alzheimer's disease, it appeared that the modified version, S. 2183, would improve the prospects for early Senate action on Alzheimer's legislation.

We can no longer delay. We must act now before the social and economic consequences burden families, health care professionals, and institutions far beyond their limits.

There appears to be increased awareness now and increased consensus that it is absolutely essential to expand biomedical and health services research, home- and community-based care and family respite, and education and training of all involved.

Since the magnitude and severity of the problem is so enormous, only a coordinated national effort can address it. Therefore, I believe some strategy such as a National Council on Alzheimer's Disease, should be established to coordinate, facilitate, and integrate the effort, and it should be representative of the Federal agencies involved, the scientists and researchers, the private institutions, the organizations, and family caregivers.

The incidence of Alzheimer's disease grows dramatically, and time grows shorter. If we do not want the baby boom to turn into an Alzheimer's boom, we must act now.

My hope is that this hearing will speed the needed legislation. I think it is particularly significant that two of our colleagues in the Senate, Senator Pressler and Senator Gore, both of whom have indicated in the past their interest and concern about numerous health issues, are both with us today to testify, and I thank you, Mr. Chairman, for your leadership and assistance on this subject.

Thank you.

[The prepared statement of Senator Metzenbaum follows:]

STATEMENT BY SENATOR HOWARD METZENBAUM BEFORE THE SUBCOMMITTEE ON AGING ON JULY 22, 1986 AT A HEARING REGARDING ALZHEIMER'S DISEASE

MR. CHAIRMAN, I THANK YOU FOR HOLDING THIS HEARING ON ALZHEIMER'S DISEASE AND RELATED DISORDERS, AND I HAVE NO DOUBT THAT MANY MILLIONS OF AMERICANS ALSO THANK YOU. THE ALZHEIMER EPIDEMIC IS A REAL AND PRESENT THREAT TO THE HEALTH OF OUR CITIZENS. UNLESS WE ACT SOON, THE GRAYING OF AMERICA COULD PROVE DEVASTATING TO OUR RESOURCES, OUR HEALTH CARE PROVIDERS AND INSTITUTIONS, AND MOST OF ALL, TO OUR FAMILIES.

BY THE YEAR 2030, THE NUMBER OF OLDER CITIZENS WILL ALMOST DOUBLE TO 21% OF THE TOTAL POPULATION - 1 IN 5. HALF OF THESE WILL BE OVER 75, - THE SENIORS MOST VULNERABLE TO ALZHEIMER'S DISEASE. THE OVER 65 YEARS ARE SUPPOSED TO BE THE "GOLDEN YEARS". BUT MORE AND MORE ELDERLY MAY FIND THAT THOSE YEARS ARE GRIM, HOPELESS STRUGGLES FOR SURVIVAL.

UNLESS WE COMMIT ADEQUATE RESOURCES NOW TO PREVENT THE TRAGEDY OF DEMENTIA, ALZHEIMER'S DISEASE COULD WELL BANKRUPT THE NATION PHYSICALLY, EMOTIONALLY AND FINANCIALLY.

I HAVE PERSONALLY KNOWN MANY COMPETENT, PRODUCTIVE PEOPLE WHO HAVE BEEN VICTIMS OF THIS DREAD DISEASE. MY GOOD FRIEND, JEROME STONE, WHOSE LOVELY WIFE WAS A VICTIM FOR MANY YEARS, IS HERE TODAY AS A WITNESS. JERRY IS THE FOUNDING PRESIDENT OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION. HE IS HERE, TO TESTIFY TO THE DEDICATION, THE BURDENS, THE NEEDS OF HUNDREDS OF THOUSANDS OF FAMILIES WHO ARE NOW CARING FOR THEIR DEMENTED LOVED ONES.

SADLY, ONE OF THE AFFLICTED FAMILIES IS THAT OF MY FRIEND AND COLLEAGUE, THE DISTINGUISHED SENATOR FROM SOUTH DAKOTA, SENATOR LARRY PRESSLER, WHO IS HERE AS A WITNESS TODAY.

MAKE NO MISTAKE ABOUT IT. THIS IS A CRUEL DISEASE THAT ROBS ITS VICTIMS OF MEMORY, OR PERSONHOOD, OF DIGNITY AND OF LIFETIME SAVINGS, TOO. NOT ONLY THE 2.5 TO 3 MILLION VICTIMS, BUT THE FAMILIES WHO CARE AND WATCH ALSO SUFFER IMMEASURABLY.

I INTRODUCED LEGISLATION SEVERAL YEARS AGO TO EXPAND RESEARCH, TO PROVIDE SOME FINANCIAL RELIEF TO FAMILY CAREGIVERS, TO URGE THE VETERANS ADMINISTRATION TO DEVELOP A CONSISTENT POLICY REGARDING ALZHEIMER'S VICTIMS.

IN THIS CONGRESS, I INTRODUCED S. 1835 AND S. 2183 WHICH WOLD PROVIDE A COMPREHENSIVE APPROACH TO THE PROBLEM OF ALZHEIMER'S' DISEASE AND RELATED DISORDERS.

S. 2183, A BILL BEFORE THIS PANEL TODAY, IS SIMILAR TO THE COMPREHENSIVE S. 1835 WHICH WAS REFERRED TO THE COMMITTEE ON FINANCE. THE ORIGINAL, S. 1835, INCLUDED ADDITIONAL PROVISIONS DEALING WITH TAX POLICY, MEDICARE, SMALL BUSINESS LOANS FOR NON-PROFIT ADULT DAY CARE, VETERANS ADMINISTRATION PROGRAMS, AND A NATIONAL COUNCIL ON ALZHEIMER'S DISEASE.

WHILE I CONTINUE TO BELIEVE THAT ALL OF THE ORIGINAL BILL, S. 1835, SHOULD BE ENACTED TO ASSURE A COMPREHENSIVE FEDERAL PROGRAM ON ALZHEIMER'S DISEASE, IT APPEARED THAT THE MODIFIED VERSION, S. 2183, WOULD IMPROVE THE PROSPECTS FOR EARLY SENATE ACTION ON ALZHEIMER'S LEGISLATION. AND WE CAN NO LONGER DELAY! WE MUST ACT NOW BEFORE THE SOCIAL AND ECONOMIC CONSEQUENCES BURDEN FAMILIES, HEALTH CARE PROFESSIONALS AND INSTITUTIONS FAR BEYOND THEIR LIMITS.

THERE APPEARS TO BE INCREASED AWARENESS NOW, AND INCREASED CONSENSUS THAT IT IS ABSOLUTELY ESSENTIAL TO EXPAND BIOMEDICAL AND HEALTH SERVICES RESEARCH, HOME AND COMMUNITY-BASED CARE AND FAMILY RESPITE, AND EDUCATION AND TRAINING OF ALL INVOLVED. SINCE THE MAGNITUDE AND SEVERITY OF THE PROBLEM IS SO ENORMOUS, ONLY A COORDINATED NATIONAL EFFORT CAN ADDRESS IT. THEREFORE, I BELIEVE, SOME STRATEGY SUCH AS A NATIONAL COUNCIL ON ALZHEIMER'S DISEASE SHOULD BE ESTABLISHED TO COORDINATE, FACILITATE, AND INTEGRATE THE EFFORT. AND IT SHOULD BE REPRESENTATIVE OF THE FEDERAL AGENCIES INVOLVED, THE SCIENTISTS AND RESEARCHERS, THE PRIVATE AND PUBLIC INSTITUTIONS, THE ORGANIZATIONS AND FAMILY CAREGIVERS.

THE INCIDENCE OF ALZHEIMER'S DISEASE GROWS DRAMATICALLY, AND TIME GROWS SHORTER. IF WE DO NOT WANT THE "BABY BOOM" TO TURN INTO AN ALZHEIMER'S BOOM, WE MUST ACT NOW. MY HOPE IS THAT THIS HEARING WILL SPEED THE NEEDED LEGISLATION.

Senator GRASSLEY. I will now turn to Senator Pressler and Senator Gore, in that order, and ask for your summaries of your statements, and to compliment you along the same lines and associate myself with the remarks of Senator Metzenbaum as he applauded each of you for your leadership in this area.

Senator METZENBAUM. Mr. Chairman, on behalf of Senator Simon, I would like to introduce a statement. He would have been here, but he is attending the funeral of George O'Brien. So I will just ask you to do that, please.

Senator GRASSLEY. Yes, without objection, that will be entered.

[The prepared statement of Senator Simon follows:]

Paul Simon

STATEMENT OF SENATOR PAUL SIMON
SUBCOMMITTEE ON AGING-COMMITTEE ON LABOR AND HUMAN RESOURCES
OVERSIGHT HEARING ON THE CARE OF PEOPLE WITH ALZHEIMER'S
DISEASE AND RELATED DEMENTIAS
JULY 22, 1986

MR. CHAIRMAN, LET ME THANK YOU FOR SCHEDULING THIS HEARING TODAY. I APPRECIATE YOU RESPONDING TO THE REQUEST OF SEVERAL OF MY COLLEAGUES AND MYSELF TO HOLD THIS VERY IMPORTANT HEARING. THIS NATIONAL HEALTH PROBLEM IS OF GREAT CONCERN TO ME.

SINCE THERE IS NO EFFECTIVE TREATMENT OR CURE FOR ALZHEIMER'S, MANY VICTIMS ARE CARED FOR IN NURSING HOMES IN THE LATER STAGES OF THE DISEASE. THE ESTIMATED COST OF CARE NOW APPROACHES $30 BILLION ANNUALLY. THIS COST ESTIMATE IS PARTICULARLY STAGGERING WHEN ONE RECOGNIZES THAT THE ELDERLY ARE THE FASTEST GROWING SEGMENT OF OUR POPULATION.

DURING A RECENT SENATE DEBATE ON A 1987 BUDGET PROPOSAL, I SUPPORTED A MEASURE TO APPROPRIATE FUNDS FOR A NATIONAL DATA COLLECTION CENTER ON ALZHEIMER'S. I WAS PLEASED WITH THE SUCCESS OF THIS MEASURE AND I AM HOPEFUL THAT THROUGH

INFORMATION GATHERING AND RESEARCH, WE WILL BE ABLE TO BRING TO AN END THE SUFFERING OF VICTIMS OF ALZHEIMER'S AND THEIR FAMILIES.

I AM PARTICULARLY PLEASED TO SEE MR. JEROME STONE OF CHICAGO, PRESIDENT OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION (ADRDA), AS ONE OF OUR WITNESSES TODAY. I WOULD LIKE TO COMMEND MR. STONE, WHO HAS BEEN NATIONALLY RECOGNIZED, FOR HIS VOLUNTEER CONTRIBUTIONS ON BEHALF OF ALZHEIMER'S VICTIMS AND THEIR FAMILIES. THE WORK OF ADRDA IN NOT ONLY EDUCATING THE PUBLIC ABOUT THIS DISEASE AND ADVOCATING FOR RESEARCH TO FIND A CURE, BUT ALSO IN PROMOTING SUPPORT TO FAMILIES HAS BEEN PARAMOUNT TOWARD ANY MOVEMENT WE HAVE OBSERVED ON THIS HEALTH MATTER. I LOOK FORWARD TO HEARING THE TESTIMONY OF MR. STONE AND OUR OTHER WITNESSES.

I HOPE THAT THE LABOR AND HUMAN RESOURCES COMMITTEE WILL CONTINUE TO ADDRESS THE LEGISLATIVE PROPOSALS INTRODUCED BY SENATOR METZENBAUM AND OTHERS. I LOOK FORWARD TO WORKING ON LEGISLATION WHICH HAS AS ITS GOAL RELIEF FROM THE SUFFERING ENDURED AS A RESULT OF ALZHEIMER'S.

Senator GRASSLEY. Senator Pressler.

STATEMENT OF HON. LARRY PRESSLER, A U.S. SENATOR FROM THE STATE OF SOUTH DAKOTA

Senator PRESSLER. Mr. Chairman, I shall summarize my remarks and place them in the record.

I want to first of all thank you, Senator Grassley and Senator Metzenbaum, for holding this hearing and for your leadership, and also my colleague, Senator Gore.

As Senator Metzenbaum has mentioned, I have a father who suffers from Alzheimer's disease, and I have learned firsthand the difficulties and the pain family members experience, but also I have learned the wonderful relationship that exists in the support groups. And you will be hearing later this morning from panels of witnesses who have done so much in the leadership of organizing those support groups, from Mr. Stone, to many others on this list who have experienced Alzheimer's, and their families who have organized support groups. And I might say that the warmth and comraderie in those groups is something I had never known existed. They are really an inspiration to the people who carry them out.

Also, I see you will be hearing from other experts, and I want to compliment the witnesses, because the list of witnesses is truly the finest people in this field.

Also, Mr. Chairman, let me say that in your opening statement you have summarized many of the facts about Alzheimer's. I shall skip over that part of my testimony for purposes of brevity. But let me point out that experts are estimating that it costs between $24 and $48 billion each year to care for patients with dementia in the United States.

These figures alone illustrate the enormity of this problem. And if we could find a key to this disease, we could actually save a lot of money by people taking care of themselves in their own homes longer. I think aside from all the human issues and the family issues, that is something in this day and age that we have to think about very seriously.

I also want to compliment the group of Congressmen and Senators who have been active on Alzheimer's disease. This core group of Members of Congress who have joined together in support of efforts to combat Alzheimer's disease has been very important. This group can be counted on for support of virtually all reasonable Alzheimer's initiatives here in Congress.

As we continue to battle Alzheimer's disease, I feel certain congressional support and awareness will continue.

Mr. Chairman, we have held many hearings on Alzheimer's disease in the past few years. As a member of the Special Committee on Aging, I have held two such hearings myself and participated in many more. The Office of Technology Assessment has done a tremendous job in putting together workshops on health services research and financing for patients with dementia.

OTA is also working on a comprehensive assessment of disorders causing dementia, which I understand will be completed this fall.

As one of the original requesters for each of these projects, I want to commend the OTA staff for their fine work in this area.

Recently I authored a letter to Health and Human Services Secretary Otis Bowen regarding Alzheimer's disease. Nine of my Senate colleagues joined me in signing this letter, which requested that Secretary Bowen maintain efforts on behalf of Alzheimer's disease as a top priority with the Department of Health and Human Services. I would like to submit this letter and Secretary Bowen's response for the record.

While all these hearings, reports, and workshops have helped to educate Congress and the public on the effects and implications of Alzheimer's disease on today's society, we still have a long road ahead of us. A certain cure or cause for Alzheimer's disease has not been discovered. A quick computer search will turn up some 30 bills specifically dealing with Alzheimer's disease that have been introduced in the 99th Congress. Personally, I would like to see each of these bills enacted. But obviously, in these times of record budget deficits, we do not have the access to funding this would require.

Therefore, it is more important than ever that we join together in our fight against Alzheimer's.

I would like to briefly explain the Alzheimer's legislation I introduced which is now pending before this subcommittee, the CARE bill, the Comprehensive Alzheimer's Assistance, Research and Education Act. This bill and its companion, H.R. 2280 introduced in the House by Representative Roybal, has three major sections.

First, creation of a national Alzheimer's education program. It emphasizes a national program that would foster and coordinate research, training and education programs relating to the cause, treatment and diagnosis of Alzheimer's disease and related disorders. It establishes an information clearinghouse to collect information from research and treatment programs and make this information available to health care professionals, professional organizations and the general public.

Second, establishment of State Alzheimer's programs. It provides for grants to States to encourage development and coordination of resources to assist victims of Alzheimer's disease and their families. Up to 25 percent of a State's grant may be used for respite care.

Third, expansion of research. It provides for expansion of the current Alzheimer's research centers. It provides grants for research on family stress management, development of health care and social systems, and continuing education of health care professionals.

I should note, Mr. Chairman, that Representative Roybal's CARE bill in the House now has 90 cosponsors. I urge our Senate colleagues to join me and the cosponsors of the Senate bill, Senators Heinz and Sarbanes, in supporting S.1736.

Enactment of this legislation as well as any of the other bills before this Committee would be a major step toward helping the victims, families, and caregivers to better understand and cope with Alzheimer's disease.

With the limited funding and time left in this session of Congress, we need to develop a set of priorities so we may work together to pass comprehensive legislation. Each of the bills before this committee addresses certain areas of the problem: Research, educa-

tion, respite care, tax relief, training, and coordination of information and resources. Each is important; however, we need to find the proper balance between our ultimate goals and the budgetary realities currently facing Congress. I stand ready to help reach these goals in any way.

I thank the committee for providing me with the opportunity to testify today. I would be happy to answer any questions.

I shall submit the remainder of my testimony and the attached documents for the record, and I thank the committee very much.

Senator GRASSLEY. Thank you, Senator Pressler.

[The prepared statement of Senator Pressler and response to question submitted by Senator Grassley follow:]

STATEMENT OF
UNITED STATES SENATOR LARRY PRESSLER
BEFORE THE SUBCOMMITTEE ON AGING
SENATE LABOR AND HUMAN RESOURCES COMMITTEE
FOR A HEARING ON
"THE CARE OF PEOPLE WITH ALZHEIMER'S DISEASE"
JULY 22, 1986

I WOULD LIKE TO BEGIN BY COMMENDING YOU, CHAIRMAN GRASSLEY, FOR HOLDING THIS HEARING ON "THE CARE OF PEOPLE WITH ALZHEIMER'S DISEASE." SERVING TOGETHER ON THE SENATE SPECIAL COMMITTEE ON AGING, YOU AND I HAVE WORKED TOGETHER ON MANY AGING ISSUES. I SALUTE YOU FOR YOUR GENUINE CONCERN AND INTEREST IN ASSISTING THE SENIOR CITIZENS OF THIS NATION. YOUR LEADERSHIP IN THIS AREA IS INVALUABLE.

I ALSO APPRECIATE THE OPPORTUNITY TO TESTIFY BEFORE THIS COMMITTEE TODAY. I COME BEFORE YOU AS A COLLEAGUE WHO HAS SPONSORED COMPREHENSIVE LEGISLATION AIMED AT ASSISTING THE VICTIMS OF ALZHEIMER'S DISEASE AND THEIR FAMILIES; AND ALSO AS A FAMILY MEMBER WHO HAS BEEN DIRECTLY AFFECTED BY THE DEVASTATING EFFECTS OF THIS INSIDIOUS DISEASE. AS MANY OF YOU KNOW, SOME YEARS AGO, MY FATHER WAS DIAGNOSED AS HAVING ALZHEIMER'S DISEASE. I KNOW FIRST-HAND THE DIFFICULTIES AND THE PAIN FAMILY MEMBERS EXPERIENCE IN CARING FOR A LOVED ONE WITH ALZHEIMER'S DISEASE.

As you know Mr. Chairman, Alzheimer's disease afflicts at least 1.5 million Americans. With our elderly population growing at an amazing rate, the number of Alzheimer's victims will continue to increase. In my home state of South Dakota, over 13.5 percent of our total population are elderly, placing South Dakota 6th in the nation for its percentage of senior citizens. It is estimated that over half of all nursing home admissions may be due to Alzheimer's disease. Experts are also estimating that it costs between $24 and $48 <u>billion</u> each year to care for patients with dementia in the United States. These few figures alone, illustrate the enormity of this problem. I have frequently said if we do not find a way to stop this disease now, it will quickly become the biggest health problem of the next century.

In recent years we have accomplished a great deal in raising public and Congressional awareness of Alzheimer's disease. We now have a "core group" of members of Congress who have joined together in support of efforts to combat Alzheimer's disease. This group can be counted on for support of virtually all reasonable Alzheimer's initiatives here in Congress. As we continue to battle Alzheimer's disease, I feel certain Congressional support and awareness will increase.

WE HAVE HELD MANY HEARINGS ON ALZHEIMER'S DISEASE IN THE PAST FEW YEARS. AS A MEMBER OF THE SPECIAL COMMITTEE ON AGING, I HAVE HELD TWO SUCH HEARINGS MYSELF, AND PARTICIPATED IN MANY MORE. THE OFFICE OF TECHNOLOGY ASSESSMENT (OTA) HAS DONE A TREMENDOUS JOB IN PUTTING TOGETHER WORKSHOPS ON HEALTH SERVICES RESEARCH AND FINANCING FOR PATIENTS WITH DEMENTIA. OTA IS ALSO WORKING ON A COMPREHENSIVE ASSESSMENT OF DISORDERS CAUSING DEMENTIA, WHICH I UNDERSTAND WILL BE COMPLETED THIS FALL. AS ONE OF THE ORIGINAL REQUESTERS FOR EACH OF THESE PROJECTS, I WANT TO COMMEND THE OTA STAFF FOR THEIR FINE WORK IN THIS AREA.

RECENTLY, I AUTHORED A LETTER TO HEALTH AND HUMAN SERVICES SECRETARY OTIS BOWEN, REGARDING ALZHEIMER'S DISEASE. NINE OF MY SENATE COLLEAGUES JOINED ME IN SIGNING THIS LETTER WHICH REQUESTED THAT SECRETARY BOWEN MAINTAIN EFFORTS ON BEHALF OF ALZHEIMER'S DISEASE AS A TOP PRIORITY WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES. I WOULD LIKE TO SUBMIT THIS LETTER AND SECRETARY BOWEN'S RESPONSE FOR THE RECORD.

WHILE ALL OF THESE HEARINGS, REPORTS AND WORKSHOPS HAVE HELPED TO EDUCATE CONGRESS AND THE PUBLIC ON THE EFFECTS AND IMPLICATIONS OF ALZHEIMER'S DISEASE ON TODAY'S SOCIETY, WE STILL HAVE A LONG ROAD AHEAD OF US. A CERTAIN CURE OR CAUSE FOR ALZHEIMER'S DISEASE HAS NOT BEEN DISCOVERED. A QUICK COMPUTER SEARCH WILL TURN UP SOME THIRTY BILLS SPECIFICALLY DEALING WITH

ALZHEIMER'S DISEASE THAT HAVE BEEN INTRODUCED IN THE 99TH CONGRESS. I WOULD LIKE TO SEE EACH OF THESE BILLS ENACTED. BUT OBVIOUSLY, IN THESE TIMES OF RECORD BUDGET DEFICITS, WE DO NOT HAVE THE ACCESS TO FUNDING THIS WOULD REQUIRE. THEREFORE, IT IS MORE IMPORTANT THAN EVER THAT WE JOIN TOGETHER IN OUR FIGHT AGAINST ALZHEIMER'S.

I WOULD LIKE TO BRIEFLY EXPLAIN THE ALZHEIMER'S LEGISLATION I INTRODUCED WHICH IS NOW PENDING BEFORE THIS SUBCOMMITTEE -- THE "CARE" BILL (THE COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH, AND EDUCATION ACT.) THIS BILL AND ITS COMPANION, H.R. 2280 INTRODUCED IN THE HOUSE BY REPRESENTATIVE ROYBAL, HAS THREE MAJOR SECTIONS:

1) CREATION OF A NATIONAL ALZHEIMER'S EDUCATION PROGRAM: ESTABLISHES A NATIONAL PROGRAM THAT WOULD FOSTER AND COORDINATE RESEARCH, TRAINING, AND EDUCATION PROGRAMS RELATING TO THE CAUSE, TREATMENT AND DIAGNOSIS OF ALZHEIMER'S DISEASE AND RELATED DISORDERS. IT ESTABLISHES AN INFORMATION CLEARINGHOUSE TO COLLECT INFORMATION FROM RESEARCH AND TREATMENT PROGRAMS AND MAKES THIS INFORMATION AVAILABLE TO HEALTH CARE PROFESSIONALS, PROFESSIONAL ORGANIZATIONS AND THE GENERAL PUBLIC.

2) ESTABLISHMENT OF STATE ALZHEIMER'S PROGRAMS: PROVIDES FOR GRANTS TO STATES TO ENCOURAGE DEVELOPMENT AND COORDINATION OF RESOURCES TO ASSIST VICTIMS OF ALZHEIMER'S DISEASE AND THEIR FAMILIES. UP TO 25 PERCENT OF A STATE'S GRANT MAY BE USED FOR RESPITE CARE.

3) EXPANSION OF RESEARCH: PROVIDES FOR EXPANSION OF THE CURRENT ALZHEIMER'S RESEARCH CENTERS. PROVIDES GRANTS FOR RESEARCH ON FAMILY STRESS MANAGEMENT, DEVELOPMENT OF HEALTH CARE AND SOCIAL SYSTEMS, AND CONTINUING EDUCATION OF HEALTH CARE PROFESSIONALS.

I SHOULD NOTE, MR. CHAIRMAN, THAT REPRESENTATIVE ROYBAL'S CARE BILL IN THE HOUSE NOW HAS 90 COSPONSORS. I URGE OUR SENATE COLLEAGUES TO JOIN ME AND THE COSPONSORS OF THE SENATE BILL, SENATORS HEINZ AND SARBANES, IN SUPPORTING S. 1736. ENACTMENT OF THIS LEGISLATION, AS WELL AS ANY OF THE OTHER BILLS BEFORE THIS COMMITTEE, WOULD BE A MAJOR STEP TOWARD HELPING THE VICTIMS, FAMILIES AND CARE GIVERS TO BETTER UNDERSTAND AND COPE WITH ALZHEIMER'S DISEASE.

WITH LIMITED FUNDING AND TIME LEFT IN THIS SESSION OF CONGRESS, WE NEED TO DEVELOP A SET OF PRIORITIES SO WE MAY WORK TOGETHER TO PASS COMPREHENSIVE LEGISLATION. EACH OF THE BILLS BEFORE THIS COMMITTEE ADDRESSES CERTAIN AREAS OF THE PROBLEM: RESEARCH, EDUCATION, RESPITE CARE, TAX RELIEF, TRAINING, AND COORDINATION OF INFORMATION AND RESOURCES. EACH IS IMPORTANT. HOWEVER, WE NEED TO FIND THE PROPER BALANCE BETWEEN OUR ULTIMATE GOALS AND THE BUDGETARY REALITIES CURRENTLY FACING CONGRESS. I STAND READY TO HELP REACH THESE GOALS IN ANY WAY.

I THANK THE COMMITTEE FOR PROVIDING ME WITH THE OPPORTUNITY TO TESTIFY TODAY. I WOULD BE HAPPY TO ANSWER ANY QUESTIONS.

QUESTION FOR SENATOR PRESSLER

I KNOW YOU HAVE EXPERIENCED AT FIRST HAND THE DIFFICULTIES OF CARING FOR A PERSON WITH ALZHEIMER'S DISEASE. GIVEN THAT YOU ARE A UNITED STATES SENATOR, MANY PEOPLE WOULD ASSUME THAT YOU WOULD HAVE THE RESOURCES TO HANDLE THE PROBLEMS PRESENTED BY THIS AND THAT SUCH CARE WOULD NOT PRESENT SUCH A PROBLEM TO YOU. IS THAT THE CASE?

SENATOR PRESSLER'S RESPONSE TO SENATOR GRASSLEY'S QUESTION:

While the financial resources may not be a problem for some families, this is only one small aspect of caring for a family member with Alzheimer's Disease. As a United State Senator, I am confronted with additional problems, the most important being that to fulfill my duties as a Senator, I must spend a great deal of time in Washington. Therefore, I cannot spend as much time with my family member as I would like.

Secondly, one must realize that the tramatic emotional burden of watching a loved one suffer indefinitely does not lessen simply because one has adequate financial resources. I am sure other family members feel the same way. The pain of watching a loved one with Alzheimer's disease is very real, and money does not lessen the pain, or make it go away.

I commend the Chairman for asking this important question. Indeed, the financing of care for Alzheimer's patients is an important topic. And, as a United States Senator, I intend to work for adequate and fair policies which enable all families access to the best care possible.

Senator GRASSLEY. Senator Gore.

STATEMENT OF HON. ALBERT GORE, A U.S. SENATOR FROM THE STATE OF TENNESSEE

Senator GORE. Thank you very much, Mr. Chairman and Senator Metzenbaum.

I, too, want to thank you for holding today's hearing and for giving me the opportunity to testify, and I too will summarize my statement.

As Senator Metzenbaum said in his opening remarks, Alzheimer's disease is extremely pervasive and misunderstood, and it has only recently become the kind of disease that strikes fear in the hearts of so many. And I think it is obvious it has been with us for a long time, but for so long it was simply confused with senility. We now know that senility always has some kind of organic cause. And Alzheimer's disease and related diseases constitute the largest cause of senility.

We have taken some steps in the Congress to approach this problem, but we owe it to the American people to do everything we possibly can to address this enormous tragedy.

In 1984, I chaired a series of congressional hearings on the House side into this disease, both in Washington and in Tennessee. I do not know that I have ever participated in hearings that had a greater emotional impact on me personally, and in getting to know the families of the victims of Alzheimer's disease, I and other members of that subcommittee formed a very strong commitment to do whatever we possibly could from then on to see if there might be some way to move closer to a solution for this problem. And of course, the problem is growing because the population is aging, and if current trends continue, by the year 2030, between 4 and 8 million Americans may suffer from the disease.

As my colleague, Senator Pressler, indicated, there are a number of bills that have been proposed, and each of these bills has much to offer, and I could commend all of them to your attention.

I am pleased to have Senator Pressler as a cosponsor on the legislation I introduced; I am pleased to join him a cosponsor of the bill that he introduced. And as I say, I commend all of them to your attention.

Let me briefly describe S.174, which is the bill I introduced. It was the first bill I introduced as a member of the Senate. About 5 minutes after I was sworn in, I took it up to the clerk. And Congressman Claude Pepper is the leading sponsor of this bill over on the House side. It is designated H.R. 524 on the House side.

It was developed with the help of the Alzheimer's disease and Related Disorders Association and is designed to compliment the congressionally mandated Alzheimer's Research Program being run by NIH. It would establish 20 regional centers for the treatment of Alzheimer's disease and would have seven principal aims: (1) to diagnose patients and counsel victims and families; (2) to assist in home care; (3) to train professionals and others in diagnosis, treatment and management; (4) to develop cost-effective methods for delivering services to patients; (5) to develop a program of both acute and long-term care for patients including care for which

medical benefits are available under Medicare and Medicaid; (6) to work with local and State public health and social service agencies and nursing homes and (7) to allow Medicare or Medicaid patients to elect to receive care at one of these designated treatment centers in lieu of traditional services.

Diagnosis and treatment are very important. In my home State, for example, the Aging Center at East Tennessee State University has made tremendous strides forward in recent years, and the work East Tennessee State is doing promises to bring some breakthroughs.

At the same time, we must do more to care for the millions of Americans who need care now. And one goal of today's hearing as I understand it is to begin assembling legislation that can start tackling more of the Alzheimer's problem right away. Along those lines, I hope that the subcommittee will consider demonstration projects to explore ways to care for those already afflicted. Important questions need answers, such as: What kind of care is available? What types of care work best? How much does it cost? An applied study of questions like these would provide caregivers with a better idea of how to help patients.

For example, one approach that has been proven to work is in-home respite care. It has become increasingly apparent that respite care in the home may be more effective and less expensive than daycare. We need to conduct more of this type of practical research to explore other approaches.

So Mr. Chairman, as we build a national consensus to confront this disease, we also have to find ways to pay for it, of course. Alzheimer's health care costs have been estimated to already be as much as $40 billion a year, as Senator Pressler mentioned in his statement. How to bear this expense could be one of the most vexing questions of our time. But we should not delude ourselves into thinking that a decision by the Congress to do nothing else with respect to this disease would be a decision not to incur a great deal of cost. We are paying an awful lot of money now. We are just not spending it effectively, as effectively as we could. We are not organizing our national effort as well as we could.

So when looking at the cost figures, let us compare what proposed remedies would cost with what we are already spending in a fashion that is not as well-organized as it should be.

Well, in conclusion, Mr. Chairman, Alzheimer's disease is a growing problem in American society. We can hope our commitment to treating and curing the disease will grow as quickly. Through the efforts of this subcommittee, we can make a difference in the fight against Alzheimer's. Life is too short for us to stand by and watch such a tragic disease take our loved ones away.

Thank you.

[The prepared statement of Senator Gore follows:]

REMARKS OF THE HONORABLE ALBERT GORE JR.
SENATE SUBCOMMITTEE ON AGING
JULY 22, 1986

MR. CHAIRMAN, THANK YOU FOR HOLDING TODAY'S HEARING, AND FOR OFFERING ME THE OPPORTUNITY TO TESTIFY. ALZHEIMER'S DISEASE IS ONE OF THE MOST PERVASIVE, MISUNDERSTOOD, AND UNRECOGNIZED HEALTH PROBLEMS IN THIS COUNTRY. WE HAVE TAKEN A NUMBER OF IMPORTANT STEPS. BUT, WE IN CONGRESS OWE IT TO THE AMERICAN PEOPLE TO DO EVERYTHING WE POSSIBLY CAN TO ADDRESS THE TRAGEDY OF ALZHEIMER'S.

IN 1984, I CHAIRED A SERIES OF CONGRESSIONAL HEARINGS ON THE DISEASE IN WASHINGTON AND TENNESSEE. AT ONE HEARING, A WOMAN WHOSE HUSBAND SUFFERS FROM ALZHEIMER'S SPOKE UP IN WORDS I WILL NEVER FORGET. "MY LIFE CAN BE DESCRIBED AS A FUNERAL THAT NEVER ENDS," SHE SAID. "I WANT MY HUSBAND BACK."

"ONCE, A FEW MONTHS AGO," SHE WENT ON, "HE ASKED ME TO GO INTO THE BEDROOM -- WE NEEDED TO TALK PRIVATELY, HE SAID. I WENT TO THE ROOM AND CLOSED THE DOOR. HE TURNED TO ME WITH TEARS IN HIS EYES AND ASKED, 'AM I LOSING MY MIND, HONEY? AM I GOING CRAZY?'"

THAT BRAVE WOMAN IS NOT ALONE. ONE OF EVERY TEN AMERICANS OVER THE AGE OF 65 HAS ALZHEIMER'S -- THAT'S OVER TWO MILLION "NEVER-ENDING FUNERALS" GOING ON DAY IN AND DAY OUT. AND AS AMERICANS LIVE LONGER, OUR CHANCES OF GETTING ALZHEIMER'S INCREASE. IF CURRENT TRENDS CONTINUE, BY THE YEAR 2030 BETWEEN 4 AND 8 MILLION AMERICANS MAY SUFFER FROM THE DISEASE.

WE ARE HERE THIS MORNING BECAUSE WE RECOGNIZE THAT SOMETHING MUST BE DONE -- AND SOON. CLEARLY, WE NEED A NATIONAL EFFORT TO RESEARCH, DIAGNOSE, AND TREAT ALZHEIMER'S. AS PART OF THE NATIONAL EFFORT, WE MUST PROVIDE SUPPORT AND ENCOURAGEMENT FOR FAMILIES TO CARE IN THE HOME, FOR THEIR LOVED ONES AFFLICTED WITH ALZHEIMER'S DISEASE.

AT LAST WE ARE BEGINNING TO RECOGNIZE JUST HOW INSIDIOUS THE DISEASE CAN BE. AT THE HEARINGS IN WASHINGTON AND TENNESSEE, THE FAMILIES OF VICTIMS CONVINCED ME THAT ALZHEIMER'S IS TOO SERIOUS AND TOO PAINFUL TO IGNORE. MORE THAN TWENTY SUBSTANTIVE LEGISLATIVE PROPOSALS HAVE BEEN INTRODUCED IN THE 99TH CONGRESS, DIRECTLY RESPONDING TO WHAT HAS BEEN CALLED THE "CRUELEST OF INCURABLE DISEASES."

CONGRESSMAN CLAUDE PEPPER AND I HAVE INTRODUCED LEGISLATION (S. 174 & H.R. 524) TO ESTABLISH 20 REGIONAL CENTERS FOR THE TREATMENT OF ALZHEIMER'S DISEASE. THE LEGISLATION WAS DEVELOPED

WITH THE HELP OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, AND IS DESIGNED TO COMPLIMENT THE CONGRESSIONALLY MANDATED ALZHEIMER'S RESEARCH PROGRAM BEING RUN BY NIH.

OUR BILL HAS SEVEN PRINCIPAL AIMS:

1. TO DIAGNOSE PATIENTS AND COUNSEL VICTIMS AND FAMILIES
2. TO ASSIST IN HOME CARE
3. TO TRAIN PROFESSIONALS AND OTHERS IN DIAGNOSIS, TREATMENT, AND MANAGEMENT
4. TO DEVELOP COST-EFFECTIVE METHODS FOR DELIVERING SERVICES TO PATIENTS,
5. TO DEVELOP A PROGRAM OF BOTH ACUTE AND LONG-TERM CARE FOR PATIENTS, INCLUDING CARE FOR WHICH MEDICAL BENEFITS ARE AVAILABLE UNDER MEDICARE AND MEDICAID,
6. TO WORK WITH LOCAL AND STATE PUBLIC HEALTH AND SOCIAL SERVICE AGENCIES, AND NURSING HOMES, AND
7. FINALLY, IT ALLOWS MEDICARE OR MEDICAID PATIENTS TO ELECT TO RECEIVE CARE AT ONE OF THESE DESIGNATED TREATMENT CENTERS IN LIEU OF TRADITIONAL SERVICES.

DIAGNOSIS AND TREATMENT ARE VERY IMPORTANT. IN MY HOME STATE, FOR EXAMPLE, THE AGING CENTER AT EAST TENNESSEE STATE UNIVERSITY HAS MADE TREMENDOUS STRIDES FORWARD IN RECENT YEARS.

THE WORK EAST TENNESSEE STATE IS DOING PROMISES TO BRING GREAT BREAKTHROUGHS.

AT THE SAME TIME, WE MUST DO MORE TO CARE FOR THE MILLIONS OF AMERICANS WHO NEED CARE NOW. ONE GOAL OF TODAY'S HEARING IS TO BEGIN ASSEMBLING LEGISLATION THAT CAN START TACKLING MORE OF THE ALZHEIMER'S PROBLEM RIGHT AWAY. ALONG THOSE LINES, I HOPE THE SUBCOMMITTEE WILL CONSIDER DEMONSTRATION PROJECTS TO EXPLORE WAYS TO CARE FOR THOSE ALREADY AFFLICTED. IMPORTANT QUESTIONS NEED ANSWERS: WHAT KIND OF CARE IS AVAILABLE? WHAT TYPES OF CARE WORK? HOW MUCH DOES IT COST? AN APPLIED STUDY OF THOSE QUESTIONS WOULD PROVIDE CAREGIVERS WITH A BETTER IDEA OF HOW TO HELP PATIENTS.

FOR EXAMPLE, ONE APPROACH THAT HAS BEEN PROVEN TO WORK IS IN-HOME RESPITE CARE. IT HAS BECOME INCREASINGLY APPARENT THAT RESPITE CARE IN THE HOME IS MORE EFFECTIVE AND LESS EXPENSIVE THAN DAY CARE. WE NEED TO CONDUCT MORE OF THIS TYPE OF PRACTICAL RESEARCH TO EXPLORE OTHER APPROACHES.

AS WE BUILD A NATIONAL CONSENSUS TO CONFRONT THE DISEASE, OF COURSE, WE MUST ALSO FIND WAYS TO PAY FOR IT. ALZHEIMER'S CARE COSTS HAVE BEEN ESTIMATED TO BE AS MUCH AS 40 BILLION DOLLARS A YEAR IN THIS COUNTRY. HOW TO BEAR THIS EXPENSE COULD BE ONE OF THE MOST VEXING QUESTIONS OF OUR TIME.

GOVERNMENT EFFORTS WILL NEED TO FOCUS MORE SHARPLY ON THE VARIOUS FINANCING OPTIONS. WE DON'T WANT TO THROW MONEY AT THE PROBLEM -- BUT WE CANNOT IGNORE THE NEEDS OF OUR NEIGHBORS. IN THIS CASE, WE NEED A PANEL OF FINANCIAL EXPERTS IN THE HEALTH CARE FIELD TO MAKE RECOMMENDATIONS TO BOTH CONGRESS AND HHS. THE SOONER WE FACE THE PROBLEM, THE MORE QUICKLY WE CAN COME UP WITH EFFECTIVE SOLUTIONS.

ALZHEIMER'S IS A GROWING PROBLEM IN AMERICAN SOCIETY -- WE CAN HOPE OUR COMMITMENT TO TREATING AND CURING THE DISEASE WILL GROW AS QUICKLY. THROUGH THE EFFORTS OF THIS SUBCOMMITTEE, WE CAN MAKE A DIFFERENCE IN THE FIGHT AGAINST ALZHEIMER'S DISEASE. LIFE IS TOO SHORT FOR US TO STAND BY AND WATCH SUCH A TRAGIC DISEASE TAKE OUR LOVED ONES AWAY.

THANK YOU.

Senator GRASSLEY. Thank you, Senator Gore.

I had a question of Senator Pressler. I did not have any of you. But Senator Pressler had to go to a Foreign Relations Committee hearing on South Africa, so I will submit that in writing to him.

Do you have any questions, Senator Metzenbaum?

Senator METZENBAUM. I do not.

Senator GRASSLEY. Thank you very much, and of course, to Senator Gore and also to Senator Pressler, please work closely with us as we will with you as we consider this legislation.

I will call now our second panel, a very distinguished group of witnesses, to be led off by the president of the Alzheimer's Disease and Related Disorders Association, Mr. Jerome Stone; following Mr. Stone will be the director of the Alzheimer's Family Support Program of the Duke Aging Center, Ms. Lisa Gwyther; and then finally, we are going to conclude with the commissioner of the New York City Department for the Aging, Ms. Janet Sainer.

Please come up. I want to recognize Mr. Stone as the first witness and also say that he deserves congratulations for his recent Presidential citation that was received for his tremendous work for the Alzheimer's Association.

I do not want you to feel intimidated in the sense of the 5-minute limitation. I will notify you of the 5 minutes so you do not need to stop right that minute, but I would like to have you go no more than 60 seconds beyond it, and I hope this is in conformity with the instructions of my staff, that you would summarize. And then, as a matter of procedure not only for this panel but for every panel, your entire statement will be printed in toto in the record, so you do not have to ask permission to do that, and you do not have to take a lot of time to thank us for holding these hearings and all that; just use your 5 minutes for your expertise, and get right into it.

Mr. Stone.

STATEMENTS OF JEROME H. STONE, PRESIDENT, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, CHICAGO, IL; LISA GWYTHER, DIRECTOR, ALZHEIMER'S FAMILY SUPPORT PROGRAM, DUKE UNIVERSITY AGING CENTER, DURHAM, NC; AND JANET SAINER, COMMISSIONER, NEW YORK CITY DEPARTMENT FOR THE AGING, NEW YORK, NY

Mr. STONE. Thank you, Mr. Chairman. I will certainly try and heed the warning.

I am delighted to appear before you, Mr. Chairman, and the distinguished members of your subcommittee. My name is Jerome Stone. I am president of the Alzheimer's Disease and Related Disorders Association.

After listening to the eloquent testimony already given, I do feel that we have many friends in court, and although Shakespeare once said, "They scoff at scars who never felt the wound," I can see that even those who are not directly affected by Alzheimer's disease know the anguish and the pain of those who are, and I appreciate that kind of confirmation of what we are doing.

Ours is the only national organization that is dedicated to combatting this dread disease. From the outset, the familes, caregivers,

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health professionals, and scientists who make up our association have held to five principal goals, which we summarize with the acronym, RECAP. I will state it very simply: Research; education; chapter formation, which in turn form family support groups—and we have some 150 chapters in 46 States and over 1,000 family support groups in every State of the Nation—advocacy of essentially-needed Government assistance at all levels, and patient and family services.

We do make a statement. Many of us have been in business all of our lives, and we are used to balance sheets and profit and loss statements. And we also have a P&L statement, and our P&L is "patience and love", and you can spell "patience" any way you want to.

With that as background, Mr. Chairman, let me begin by thanking you and your colleagues for the support, understanding and compassion you have lent to this effort.

Most recently, we were pleased to join with you in cosponsoring two workshops to examine the health service needs of Alzheimer victims and to explore means of financing those services.

Mr. Chairman, I think we can all agree that a great deal has been accomplished in recent years. When I received your gracious invitation, it brought me back fullsweep to some 6 years ago when I gave testimony before this very same committee. Senator Eagleton was the chairman at that time. I said then that Alzheimer's disease was a silent epidemic that was sweeping the country and that it was of extreme urgency that we get this message across to our citizens.

I pointed out then that there was a quotation from Houseman which goes: "I, a stranger, alone and afraid in a world I never made." And that is true of not only the Alzheimer's victim, but the Alzheimer's victim's entire family.

Now this message, to a good extent, has been brought to this country. The general public now has a far greater understanding of the threat that Alzheimer's disease poses for a rapidly growing segment of our population; because of what you and your colleagues have done with the Federal research budget, we have seen a substantial increase in the amount of scientific interest in this field. It is reported, in fact, that there has been a tenfold increase in the number of scientists studying this problem.

But I also think we must be mindful, as one Government publication describes it, that a diagnosis of Alzheimer's disease still carries with it a sentence of eventual mental emptiness. For, while new scientific knowledge is helping to reduce the degree of impairment resulting from Alzheimer's disease, science is still unable to prevent it, cure it, or stop its progression.

Although research funding has increased, the total spent on finding a cause or cure still amounts to less than one-tenth of 1 percent of the $40 billion spent annually to care for Alzheimer's disease victims.

To put it in a more graphic way, we are spending some $20 per victim on research as against an average of $16,000 per victim for caregiving. As a man who has devoted himself to business all of his life, there is something wrong in that risk-benefit relationship.

This leads me to the topic of this hearing. How do we better serve the needs of the 2.5 to 3 million persons who currently suffer from Alzheimer's disease.

In terms of the issue at hand, I interpret that to mean that we must not overlook desperate needs of patients and families who each day struggle with the physical emotional and financial hardships associated with Alzheimer's disease. Unfortunately, Government at all levels has paid far too little attention to those people, at least until recently.

In your invitation to me, you asked that I comment on legislative proposals now pending in the Senate. I have taken the opportunity to re-read the bills introduced a few months ago by Senators Metzenbaum and Pressler. Also, within the last few days, I have had a chance to look over a preliminary draft of the chairman's bill. In a nutshell, my response is: Yes, a thousand times yes.

The fact is, Mr. Chairman, each of these bills in its own way addresses issues that are of vital concern not just to ADRDA and its members, but to all of society, as well.

As I see it, the common thread running through each of the bills is the recognition, finally, that society has an obligation to help alleviate at least some of the burden now borne almost entirely by individuals and families. As the authors of these bills state in no uncertain terms, discrimination by nursing homes against Alzheimer's disease victims cannot be tolerated; victims of this disease have a rightful claim to Federal disability benefits.

Senator GRASSLEY. Could you summarize in 1 minute?

Mr. STONE. Lastly, these bills recognize that the partnership between Government and the voluntary sector offers the best mechanism for reaching those most in need of help.

To conclude, Mr. Chairman, it is obvious that our current health care delivery system does little to lessen the burden of caring for the Alzheimer's disease patient. The recurring theme in nearly every case we see reveals the difficulty of finding both medical and social resources for the diagnosis, management and care of the patient. As you know, Medicare does not begin to handle the cases at hand.

I indicated, as was indicated before by Senator Gore, I believe, that in-home care is less costly than care in the nursing home and even respite care in-home is less costly than respite care outside. We have to give attention to these problems.

In my testimony there is a letter that describes the anguish and pain, in very simple terms, of an Alzheimer's caretaker. I submit that for the record as just one example of the thousands who write to us for help and support.

Mr. Chairman, if I may just conclude, we have made a start. We have made a very good start in 6 years, and we have gone some way. But this is just the first step. And as a poet says, we have miles and miles to go before we sleep. I thank you for helping us in this crusade.

Senator GRASSLEY. Thank you, Mr. Stone.

[The prepared statement of Mr. Stone and the Alzheimer's Disease and Related Disorder Association and responses to questions submitted by Senators Grassley and Metzenbaum follow:]

Statement

of the

Alzheimers Disease and Related Disorders Association

to the

Subcommittee on Aging
Committee on Labor and Human Resources

Presented by

Jerome H. Stone, President

July 22, 1986

Mr. Chairman and members of the Subcommittee:

My name is Jerome Stone and I am President of ADRDA, the Alzheimer's Disease and Related Disorders Association.

Mr. Chairman, let me just say that ours is the only national organization dedicated to combating this dreaded disease called Alzheimer's. From the outset, the families, care givers, health professionals, and scientists who make up our Association have held to five principal goals and this summary is a recapitulation that, by the usage of an acronym, I have shortened to RECAP:

* Research aimed at finding the cause and cure for Alzheimer's disease;

* Education of the general public, health professionals, and care givers:

* Chapters; the formation of network that has grown to 150 chapters in 46 states and over 1,000 family support groups;

* Advocacy of essentially-needed government assistance; and

* Promotion of patient and family services.

With that as background, Mr. Chairman, let me begin by thanking you and your colleagues for the support, understanding, and compassion you have lent to this effort in the past. Most recently, we were pleased to join with you in co-sponsoring two workshops to examine the health service needs of Alzheimer's victims and to explore means of financing those services.

Research: Hope for the Future

Mr. Chairman, I think we can all agree that a great deal has been accomplished in recent years. When I received your gracious invitation it brought me back full sweep to 6 years ago when I gave testimony before this very subcommittee. I said at that time that Alzheimer's disease was a "silent epidemic" that was sweeping the country, and that it was of extreme urgency that we get this message across to our citizens. With all that has been said and written about it--and with the input given by ADRDA--the general public now has a far greater understanding of the threat Alzheimer's disease poses for a rapidly growing segment of our population. And because of what you and your colleagues have done with the federal research budget, we have seen a substantial increase in the amount of scientific interest in this field. It is reported, in fact, that the number of scientists devoting themselves to this effort has increased ten-fold just in the last decade.

But I also think we must be mindful that, as one government publication describes it, a diagnosis of Alzheimer's disease still carries with it a sentence of eventual mental emptiness. For while new scientific knowledge is helping to reduce the degree of impairment resulting from Alzheimer's disease, science is still unable to prevent it, cure it, or stop its progression.

And although research funding has increased, the total spent on finding a cause or cure still amounts to less than one-tenth of one percent of the $40 billion spent annually to care for victims. To put it another way, we are spending $20 per victim on research, as against an average of $16,000 per victim for care giving.

Meeting the Needs of Patients and Families

Which leads me to the topic of this hearing--how do we better serve the needs of the 2.5 to 3 million persons who currently suffer from Alzheimer's disease?

Mr. Chairman, the historian Toynbee once wrote that "a society's quality and durability can best be measured by the respect and care given its elderly citizens." In terms of the issue at hand, I interpret that to mean that we must not overlook the desperate needs of patients and families who, each day, struggle with the physical, emotional, and financial hardships associated with Alzheimer's disease.

Unfortunately, government at all levels has paid far too little attention to these people--at least until recently.

Review of Pending Legislation

In your letter of invitation to me you asked that I comment on legislative proposals now pending in the Senate.

I have since taken the opportunity to re-read the bills introduced a few months ago by Senators Metzenbaum and Pressler. Also, within the last few days I have had a chance to look over a preliminary draft of the Chairman's bill. In a nutshell, my response is: yes, yes, and yes.

The fact is, Mr. Chairman, each of these bills in its own way addresses issues that are of vital concern, not just to ADRDA and its members, but to all of society, as well.

As I see it, the common thread running through each of the 3 bills is the recognition, finally, that society has an obligation to help alleviate at least some of the burden now borne almost entirely by individuals and families. As the authors of these bills state--in no uncertain terms--discrimination by nursing homes against Alzheimer's victims cannot be tolerated; victims of this disease have a rightful claim to federal disability benefits; and a partnership between government and the voluntary sector offers the best mechanism for reaching those most in need of help.

Service-Related Research

I also want to voice our strong support for those efforts aimed at stimulating the development of alternative delivery systems, as well as mechanisms for financing long-term care for victims of Alzheimer's disease.

Mr. Chairman, our current health care delivery system does little to lessen the burden of caring for the Alzheimer's patient. In fact, a recurring theme in the history of each family's problems is the difficulty experienced in finding both medical and social resources for the diagnosis, management, and care of the patient.

Medicare, for example, pays hospital, physician, and laboratory services required for the diagnosis of patients, but excludes the services that are required to provide or assist with daily care. As a result, families are left to shoulder the burden for respite services, attendant care, personal care, and adult day care. Eventually, the only options left to them are to either become emotionally bankrupt by providing all needed care directly or become financially devastated by paying others for that care.

Our experience has been that the vast majority of families opt for home care over nursing home placement. It is also more economical in scope as home care costs are approximately

$12,000 annually, as against nursing home average costs of $24,000 annually. To help overcome those problems requires that systems be developed which families can turn to for direct care and guidance in the management of Alzheimer's patients. We believe that the emphasis here should be on developing an integrated continuum of care--including community-based and in-home services.

To emphasize the point Mr. Chairman, let me read just one communication that is an example of thousands that we receive.

"I may be out of line writing for advice, but I am at my wits end. Perhaps you may find time to answer my question.

"I'll start from the beginning. My husband went to the hospital on 2/22/85 for an examination. The psychiatrist made him stay there a week for tests. In the interim, he had a stroke on the right side, double Lubar (I hope it's spelled right), pneumonia, was in a semi-coma for three weeks, and lost his swallow. He had to have an operation so that he can be fed through his stomach. Doctors also diagnosed Parkinson's. Results--although he walked into the hospital, he has not been on his feet since. He is a complete vegetable. Cannot even hold a tissue in his hand. He has become completely rigid. On November 29, 1985, I was fortunate to enter him into a nursing home. The nursing home diagnosed Alzheimer's and said he did not have Parkinson's. He still cannot swallow and is being fed by the stomach tube.

"It's seven months now that he is in this home. Since that time he has now become radical and quite agitated. Curses all the time and strikes out at everyone. The psychiatrist has given him Ativan in the morning, supposedly to calm his nerves. In the evening, Sincquan, results, without fail, at twelve noon he becomes agitated and starts to curse and dates back to a past I never knew about. By 2:30 p.m. he is unbearable and strikes out at me with his hands. I have all to do to avoid being hurt. When we put him to bed he continually chatters as if he were talking to his old working buddies.

"I have spoken to the head nurse, the doctors, and the psychiatrist and they say it's the disease. I wonder, could it be possible that the two medications are working against one another."

Again, Mr. Chairman, this is just a sample of the anguish that confronts the families and loved ones of Alzheimer's victims. But I think this letter underscores the desperate need in this country for a system of health and social care that can help ease some of the burden.

Health services research can provide us with the knowledge required to construct responsive, high-quality, and cost-effective systems to meet the needs of Alzheimer's patients and families. We, therefore, support efforts to target federal resouces on developing new and innovative delivery systems.

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Clearinghouse activity

Finally, Mr. Chairman, I want to emphasize the need for a resource that scientists, health professionals, and family members, alike, can readily access for information and help. For example, there is presently no single source for providing a rural physician with the latest advances in the diagnosis and treatment of an Alzheimer's patient. And while our Association strives to reach as many families as possible, we know that many others are lost, confused, or discouraged from seeking the help of others.

We therefore support the proposal that a national clearinghouse be established to compile, archive, and disseminate information on Alzheimer's disease. Furthermore, our Association stands ready to assist in this effort in whatever way we can.

Thank you Mr. Chairman. I will be glad to answer any questions you may have.

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National Program to Conquer Alzheimer's Disease

Submitted by the

Alzheimer's Disease and Related Disorders Association

April 1986

INTRODUCTION

Based on his study of the world's great civilizations, the historian Toynbee concluded that a society's quality and durability can best be measured "by the respect and care given its elderly citizens." That being the case, never before has the measure of this country's commitment to the elderly been so critically important.

The challenges ahead

The rapid increase in the elderly population has given rise to a host of medical, economic, and social challenges which, if left unanswered, threaten a hemorrhaging in our society. And nowhere are those challenges more evident or more threatening than for the families and loved ones of the more than 2.5 million persons now suffering from a deadly neurological disorder known as Alzheimer's disease.

A national association responds

From the time the Alzheimer's Disease and Related Disorders Association (ADRDA) was first created in late 1979, the families, care givers, health professionals, and scientists who make up the organization have strived to mount a national effort to combat this dread disease. That effort includes:

* RESEARCH aimed at finding the cause and cure for Alzheimer's disease
* EDUCATION of the general public, health professionals, and care givers
* CHAPTER formation of a nationwide family support network
* ADVOCACY of essentially-needed government assistance
* and PATIENT and FAMILY SERVICES

In furtherance of these goals, the ADRDA submits the following National Program intended to serve as a guide in helping to meet some of the challenges brought on by Alzheimer's disease.

The growing threat of Alzheimer's disease

Medical researchers have established that Alzheimer's disease, the most widespread form of dementia disorders, is not simply a part of the aging process -- as evidenced by the fact that many of its victims are in their forties and fifties. Yet for some reason the vast majority of Alzheimer's sufferers are elderly persons.

According to the U.S. Public Health Service, Alzheimer's disease affects at least one person in twenty between the ages of 65 and 75, and every fifth person over 80 years of age. It follows, therefore, that as the number of elderly persons grows society can expect to encounter a substantial increase in the incidence of Alzheimer's disease and related disorders.* Apart from causing widespread human suffering, the disease will then carry particularly severe social and economic implications, as families, health professionals, and institutions are strained far beyond their limits.

Of course, from a public health perspective there can be no doubt that Alzheimer's disease has already reached epidemic proportions.

*Today, the elderly constitute about 11 percent of the total U.S. population. By the year 2030, the Bureau of the Census projects that 21 percent of the population, 64.5 million persons, will be age 65 and older. Nearly half of that total will be over age 75.

EXPANDING SUPPORT FOR MEDICAL RESEARCH

"The tacit assumption in our society that everyone will eventually become "senile" must be put aside. The expected norm should be that of a vigorous, intellectually active aging process."

--Dr. Robert Katzman
Professor and Chair, Department of Neurosciences, University of California at San Diego

Eighty years have elapsed since a German neurologist named Alois Alzheimer first described the effects of a progressive fatal dementia on a 51-year old patient. But it is only in the past decade that the disease which bears his name has received major research attention. Since 1976, research funding provided through the National Institutes of Health has increased from $4 million to nearly $50 million annually. Over the same period, the number of scientists studying the disease in the U.S. has jumped at least tenfold.

With greater federal involvement and increased scientific interest have come promising new research findings. One of the major advances over the past decade was the discovery that Alzheimer's patients often suffer from certain biochemical abnormalities in the brain. Most strikingly, they lack an enzyme that helps produce an important chemical messenger, or neurotransmitter, involved in learning and memory. In other studies, scientists have discovered similarities in protein fragments found in the damaged areas of the brain and in the brain's blood vessels, suggesting that perhaps science is moving closer to finding the underlying cause of Alzheimer's disease.

More recently, scientists have begun to suspect that the symptoms of Alzheimer's disease can be associated with loss of specific populations of brain cells. This finding could suggest that relatively normal brain function might be restored if the function of the damaged brain areas could be compensated for or replaced.

But in spite of this remarkable progress, as one government publication describes it, a diagnosis of Alzheimer's disease "carries with it a sentence of eventual mental emptiness."

In other words, there is still much to be done. For while new knowledge is helping to reduce the degree of impairment of Alzheimer's victims, science is still unable to prevent the disease, cure it, or stop its progression. And although research funding has increased in recent years, the total spent on finding a cause or cure still amounts to less than one-tenth of one percent of the $32 billion spent annually to care for victims of Alzheimer's disease.

Recommendations:

* That federal support for research on Alzheimer's disease be assigned a high priority at the National Institute on Aging, the National Institute of Neurological and Communicative Disorders and Stroke, and the National Institute of Allergy and Infectious Diseases.

* That funding for research on Alzheimer's disease be increased to at least $75 million in fiscal year 1987.

STRENGTHENING ALZHEIMER'S DISEASE CENTERS

"Full support of the Alzheimer's disease centers program is a crucial element in this war. In good conscience, we cannot recruit a cadre of scientific soldiers and send them into battle without the ammunition they need to keep fighting."

--Dr. David Drachman, Professor and Chair of Neurology at the University of Massachusetts Medical School.

From a scientific standpoint, there are a number of issues surrounding Alzheimer's disease that must to be addressed, not the least of which is finding a clinical diagnostic procedure for identifying Alzheimer's patients. Recognizing that a mechanism was needed that would address several of these problems simultaneously, two years ago Congress and the President launched a new and innovative effort designed to complement the work being conducted by independent researchers.

Since 1984, ten Alzheimer's research centers have been established -- each having clinical demonstration units together with a staff of investigators drawn from various scientific disciplines. As required by Congress, the ten centers are administered by the National Institute on Aging, working in cooperation with the National Institute of Neurological and Communicative Disorders and Stroke, the National Institute of Mental Health, and the National Institute of Allergy and Infectious Diseases.

The ten existing centers have already begun to have a dramatic impact on the status of research into Alzheimer's disease. As a result of the centers program, for example, a network of over 100 scientists throughout the country have begun to work together, sharing ideas, knowledge, and resources. Among other things, the participating scientists have already begun to standardize the diagnostic instruments used in identifying Alzheimer's disease.

Unfortunately, budget cutbacks threaten to weaken the centers program and slow the pace of scientific advances -- at a time when promising research leads point to the need for a stronger commitment to this effort. Additional funding in the amount of $2 million is required simply to maintain the basic centers program. Beyond that, an additional $5 million would permit the ten centers to expand clinical data gathering activities and support work on new and emerging research leads.

Recommendations:

* That an additional $2 million be provided in fiscal year 1987 to more adequately support the activities of the ten existing research centers.

* That an additional $5 million be provided to expand both basic research projects and clinical activities.

* That an additional $2.2 million be appropriated to support the establishment of two new research centers.

PROVIDING FAMILY SUPPORT SERVICES

According to the National Center for Health Statistics, over eighty percent of all home care is provided to the chronically ill elderly by family members. For the families of Alzheimer's victims, this usually entails mobility assistance, personal care, and household assistance.

Apart from placing an enormous financial burden on families, meeting the extensive needs of an Alzheimer's victim often results in severe stress and family dysfunction, manifested as physical illness, anxiety, depression, and family conflict. This is due, in large part, to the fact that Alzheimer's disease usually runs an agonizingly slow course, lasting anywhere from five to twenty years. Recognition of this fact has led to the development of programs designed to help ease the burden on caregivers; foremost among these has been the development of an extensive family support network by the Alzheimer's Disease and Related Disorders Association.

But peer support is clearly not enough. Family caregivers are in desperate need of a wide range of services, including respite care, adult day care, transportation, administrative and legal assistance, and in-home personal and medical services.

Recommendations:

* That the federal government forge a partnership with state and local agencies to launch a nationwide effort to help meet the needs of families caring for Alzheimer's victims. In so doing, government agencies at all levels should draw upon the knowledge and expertise of the Alzheimer's Disease and Related Disorders Association.

* That the Administration on Aging be directed to support exemplary projects to serve as models for rendering family support services. To the extent feasible, this effort should be carried out through a partnership arrangement with national voluntary organizations, such as the Alzheimer's Disease and Related Disorders Association.

* That the federal government offer subsidized loans to public and private nonprofit institutions to finance the development of respite care programs and adult day care centers for Alzheimer's victims and their families.

* That the National Institute of Mental Health continue its research on the family stress problems related to the care of Alzheimer's victims.

MEETING THE COSTS OF LONG-TERM CARE

Long-term care is, of course, a growing national concern. In his most recent State of the Union Address to Congress, President Reagan focused attention on the fact that "devastating illness can destroy the financial security of a family."

Nowhere is that more evident than with families struggling to cope with Alzheimer's disease, for the nature of this illness is such that the long-term care needs of its victims most often arise at a time when the family's economic and social resources -- including savings, pensions, and other assets -- are dwindling. Furthermore, the care and treatment of Alzheimer's patients is deemed "custodial" and specifically excluded from coverage under Medicare and practically all private health insurance plans. Consequently, the catastrophic costs of caring for an Alzheimer's victim are borne almost entirely by their families. And while Medicaid offers some help, this program most often favors institutionalization -- and is available only after a family has exhausted nearly all of its resources. (Of course, all of these problems are more pronounced when victims have no family or loved ones to turn to for help and support.)

To further compound the problem, families of Alzheimer's victims frequently encounter difficulties in obtaining access to nursing home care, since many facilities prefer short-stay, Medicare or privately-insured patients.

Recommendations:

* Federal policies should be developed which stimulate a broader range of alternative programs and services. To this end, Medicare coverage should be extended to victims of Alzheimer's disease; the Secretary of HHS should be directed to authorize Medicare waivers and home health care for these individuals.

* Far more emphasis (and resources) should be devoted to health services research on alternative delivery systems. A major portion of this research ought to be focused on developing an intergrated continuum of care, including cost-effective strategies for expanding community-based care and in-home services.

* Federal statutes should expressly prohibit nursing homes from discriminating in the acceptance or refusal of individuals as patients on the grounds that those individuals are on Medicaid or are victims of Alzheimer's disease.

* Families and care givers should be allowed a tax deduction or refundable tax credit to help defray the added costs associated with caring for an Alzheimer's victim at home.

* Any federal and/or private initiative to address the need for catastrophic or chronic illness insurance should include coverage for victims of Alzheimer's disease.

ENSURING EQUITABLE TREATMENT UNDER FEDERAL DISABLILITY PROGRAMS

The Social Security Administration has national responsibilty for the administration of both the Social Security Disability program and the Supplemental Security Income (SSI) program. The former provides cash benefits to those disabled workers and their dependents who have contributed to the social security trust fund; the latter provides for a minimum income level for the needy aged, blind, and disabled who qualify because of financial need. Under both programs, the definition of disability is the same: "an inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." (The decision as to whether an applicant is disabled, as defined by law, is made by a special disability determination unit in each state.)

Although federal statutes do not preclude benefit payments to Alzheimer's victims, the guidelines used to determine eligibility are rather vague when it comes to this disease. This, in turn, has led to wide variations from region to region, resulting in an uneven policy toward individuals who hold a rightful claim to benefits.

Recommendations:

* Federal regulations and guidelines used in evaluating disability claims should be amended to include specific reference to Alzheimer's disease and related disorders.

* A mechanism should be established whereby the most current scientific knowledge available to the National Institutes of Health is communicated to those responsible for overseeing and administering disability programs.

* Government agencies, working together with the medical and scientific community and ADRDA, should devise specific assessment tools for use by examining physicians.

ESTABLISHING A CONSISTENT POLICY FOR VETERANS WITH ALZHEIMER'S DISEASE

The Veterans' Administration currently has no uniform nationwide policy regarding the care of veterans with Alzheimer's disease. As a consequence, some victims of the disease are admitted for treatment at VA medical facilities, while others are denied admission or referred elsewhere. In other instances, patients are being forced to leave VA facilities, thereby disrupting their care and placing even greater strain on families.

Recommendations:

* The VA should develop a fair and consistent policy with respect to the care and treatment of Alzheimer's victims. That policy, in the form of written guidelines, should be distributed to VA installations throughout the country.

* Local VA facilities should be instructed to develop and implement screening, couseling, and treatment programs for veterans and their families.

* The eligibility requirements for veterans diagnosed as having Alzheimer's disease should be lowered to age 50.

* A portion of VA intermediate-care hospital beds, perhaps ten percent, should be set aside for the care of veterans suffering from Alzheimer's disease and related organic brain disorders.

* The VA should institute a system of enrollment and tracking to permit greater coordination of inpatient care and community-based services.

* Pilot studies and/or model projects undertaken by the VA should take into account the special needs of veterans suffering from Alzheimer's disease.

MEETING TRAINING AND EDUCATION NEEDS

"To the extent that individuals can be trained to help themselves and contribute to society, they preserve their autonomy and morale and they free formal and informal providers for other productive activities."

-Dr. Robert N. Butler
Professor of Geriatrics,
Mount Sinai School of
Medicine

Despite a growing awareness of the extent and burden of dementias such as Alzheimer's disease, there still exists a serious shortage of trained personnel, including research investigators, hospital and nursing home staff, safety and transportation personnel, home health aides, and family members.

Recommendations:

* Greater emphasis should be placed on career development of faculty and research investigators. As part of this effort, NIH should (1) expand the number of National Research Service Awards in the field of neuroscience, with particular emphasis on Alzheimer's disease and (2) strengthen the training component of the specialized Alzheimer's research centers.

* Clinical training needs must be re-evaluated in light of new research findings. Specifically:

  - New training curriculum must be developed which targets on treating persons with Alzheimer's disease; special attention should be paid to basic training (and continuing education) for clinical care providers

  - The Secretary of HHS should institute special training programs aimed at nursing home personnel, home health aides, pathologists, medical examiners, safety and transportation personnel, and families.

* Special emphasis should also be placed on the needs of special populations, such as minorities and the frail elderly.

PROMOTING COORDINATION AND PUBLIC AWARENESS

The fundamental need exists for greater cooperation and coordination among the several research institutions, health care providers, and families now engaged in one facet or another of this national problem. Furthermore, greater public awareness is essential if society hopes to overcome the growing challenge of Alzheimer's disease.

Recommendations:

* A national advisory council should be established to help develop, encourage, and guide research on Alzheimer's disease, as well as to serve as a mechanism for conveying new information and ideas to physicians, nurses, care givers, and family members. The council, with the full support of federal agencies, should promote collaborative efforts among those agencies, university research centers, pharmaceutical houses, and others throughout the medical and scientific community.

* The council, as well as key federal, state, and local agencies should utililize the knowledge and expertise of the Alzheimer's Disease and Related Disorders Association.

RESPONSES OF MR. STONE

I noted your support for the idea of a clearinghouse. Is it correct that your Association is now establishing a clearinghouse? If so, why would we need to establish one by legislation?

Mr. Chairman, we do not have a clearinghouse per se, but we do strive to meet the information needs of families and caregivers. As I indicated in my testimony, we are the only national organization representing the families and loved ones affected by this horrible disease. In very practical terms, we have set a duel challenge for ourselves. ADRDA strives to ease the burden on families through a nationwide network of chapters and family support groups. At the same time, we support research aimed at finding a cure and treatment for Alzheimer's disease.

Nevertheless, we are a privately operated and funded organization and, therefore, are somewhat limited in what we can do without additional resources. That is why we support legislation aimed at establishing a nationwide clearinghouse that would serve the information needs not only of families, but of scientists, physicians, and health professionals as well.

(Follow-up) Now, presuming that we should go ahead with such a clearinghouse, are you in a position to say what would be required, should such a clearinghouse be lodged with a private, nonprofit organization, in the way of staff, computer support, space, postage, and so on?

Quite frankly, Mr. Chairman, ADRDA is already fulfilling many of the critical information needs of families. In my estimation, if Congress agrees that this is of vital importance the most prudent and resourceful course would be to add to what is already being done--not start anew. In other words, ADRDA would welcome the opportunity to work in partnership with the NIH on establishing and operating a clearinghouse.

It is difficult to estimate what resources would be required to plan and operate a national clearinghouse without a clearer sense of its full mission. However, I would venture to say that between $500,000 to $1 million would be sufficient to support such an effort.

Mr. Stone, you noted in your testimony that nursing homes are discriminating against Alzheimer's victims.

I presume that where this does happen it is because of the heavy care demands that Alzheimer's patients make on a nursing home's staff. Could you elaborate a bit on the reasons why a nursing home might discriminate against Alzheimer's victims?

And, as part of the same question, what kind of documentation do you have of this? Since it is usually said, as I did in my opening statement, that half to two-thirds of nursing home patients may be suffering from dementia, it would appear that large numbers of dementia victims are getting into nursing homes.

As you know, Alzheimer's disease is a progressive neurological disorder that runs a prolonged course, lasting anywhere from 5 to more than 20 years. Of course, nursing homes may have a variety of reasons for turning away Alzheimer's patients but, no doubt, the average length of stay and level of care and supervision required are factors in the decision. Also, as has been pointed out so often, Medicare does not cover the costs of caring for Alzheimer's victims. By the time they reach the nursing home stage, many victims are dependent upon Medicaid for financial assistance. Oftentimes, nursing homes would prefer instead to admit private-pay or Medicare patients.

As is the case with so many aspects of this problem, there is no definitive data on the extent of discrimination against Alzheimer's patients. I can say with certainty, however, that our Association hears horror stories from families throughout the country. And I should add that some of the problems relate back to Veteran's Administration hospitals.

Finally, I would add that while dementia patients do make up a large part of the nursing home population, the question to ask is how many of those admissions came only after one or more rejections by other institutions.

You referred also in your statement to federal disability benefits. I understand that your Association's national program statement recommends that federal disability regulations be amended to include specific reference to Alzheimer's disease and related disorders.

Where do we stand with this matter? Is there any effort underway at present in the federal establishment to do this?

At the moment, we are still working towards a policy that treats Alzheimer's patients in an informed, fair and equitable manner.

As you noted, our Association has called for a change in the way state claims examiners handle cases involving Alzheimer's disease. We have asked that the guidelines used by examiners be rewritten on the basis of the latest scientific and medical knowledge about this disorder.

We do hold out some strong hope that this situation will be corrected soon. Recently, the House passed its version of the Labor-HHS appropriations bill, containing a special directive to the Social Security Administration regarding disability benefits. Under this provision, the SSA would be required to develop new criteria for examining claims by Alzheimer's patients and report back to Congress by the end of this year.

Once these new guidelines are in place we expect that patients will be awarded their rightful benefits.

You noted that families experience difficulty in finding the medical and social resources for diagnosis, management and care of the patient.

Now, what exactly are you referring to here: the lack of those resources in some or most localities, the difficulty of paying for them, or the difficulty of finding out about what exists?

Mr. Chairman, all are contributing factors to the problem. As we learned from the recent workshops on Alzheimer's disease, this nation is in desperate need of a co-ordinated health care and care services delivery system that can respond to this growing segment of the population.

ADRDA is concerned about its constituency's expressed need for less costly forms of care, more knowledgable and understanding service providers. In short, a high quality, affordable, consistently accessible continuum of care services.

The need for a continuum of care services cannot be stressed strongly enough. Because from that point in time when an individual is diagnosed as having Alzheimer's disease, through to his/her demise, there exists a time continuum, from 5 to 20 years, during which the victims and the family members will always require one or more services. A sense of a system of planned services for throughout the continuum can be reassuring and supportive. The current fragmented system of services, however, places increased demands and stress on already overburdened caregivers.

Alzheimer's disease impacts not just its victims, but the family as well. Most particularly, the patient's immediate caregiver shares the crushing burden of the disease as it unrelentingly pursues its dehumanizing downward course. At this time, there is no medical treatment available for the patient for extended periods during the long course of the disease. And, not infrequently, the caregiver is weakened by or succumbs to a stress-related disorder as a result of the debilitating caregiving process.

When family caregivers speak of affordable care, most often they speak of respite care to provide relief for the caregiver. Respite care comes in several options to serve the needs of the patient and the family. It may be provided through Adult day care, In-home care, Short-term Institutional care. There are other emerging options. Respite care can benefit the patient. However, equally important, it provides the caregiver blessed relief from the burden and constraints of the 36 hour day of caregiving. It allows time for personal business, rest and relaxation, and even time for re-creation, so that the caregiver may return refreshed to again resume the caregiving role.

Here's another persepctive on Adult Day Care and In-Home Care: As it is now, many spouses and adult children try to provide for their patient at home while attemtping to continue in their full time employment. Without these services it is almost impossible to do so. Often they must take early retirement.

Current financing programs, be they federal or private, do nothing to relieve the enormous emotional and financial burdens on families. Beyond that, even those families that have adequate resources are hard-pressed to locate the services, such as respite care and adult day care, that they so desperately need.

Sen. Metzenbaum

Mr. Stone, who should participate in developing recommendations for systems of financing long term Alzheimer patient care?

To develop the most cost-effective, responsive policies is a task that requires a solid partnership of effort. Government agencies such as the National Center for Health Services Research, as well as the Health Care Financing Administration must be involved. So too, must private health insurers, medical sociologists, and those health specialists skilled in functional assessment and patient management. Most importantly, I would urge government leaders not to overlook the practical experience of organizations such as ADRDA.

Quite frankly, the National Advisory Council you propose in S. 2183 would be an appropriate way of attacking this problem.

In order to extend services to the largest number possible, do you believe that fees could be charged for such services as home health care, home management assistance, adult day care, etc, perhaps on a sliding scale?

I believe this approach would work so long as the fee schedule takes into account all of the other financial demands on caregivers.

In the long run, this approach is not only good social policy, but good economic policy, as well. The vast majority of care givers, as you know, prefer to care for their loved ones at home. If they have some help in their struggle, perhaps we can avoid the risk that society ends up with two victims on its hands--the patient and care giver.

There is also another important point I feel should be made here. Health planners indicated that family member caregivers can be regarded as an important component in the health service provider system. They fulfill an important role that provides relief for the system. ADRDA has long felt that support of the caregiver in his role by some form of compensation, tax credits or shared cost of respite care would be appropriate.

Would a registry of professionals, including neurologists, occupational and physical therapists, geriatricians, and social workers be helpful to families?

Most certainly. That is why we would encourage the establishment of a national clearinghouse to make available this type of information.

To what extent are state and local governments involved in the effort to assist with supportive services?

In some respects, Senator, state and local agencies are far ahead of the federal government. At last count, 17 states had established their own task forces to examine the problems facing Alzheimer's families and to come up with support systems. Some--like California, Massachusetts, and Ohio, Illinois, Maryland--

further along than others. Still, it is important that the federal government recognize that this is a national problem, not one confined to certain states or regions. Unless there is some overall leadership and coordination, we run the risk of some unproductive duplication by groups working in different locations.

Apart from health services research, what do you see as the most critical need in patient and family services?

Patients and families face so many difficult problems, but far and away the pressing need is for adult day care and In-home care services. They can in many instances help caregivers stay in the workforce thereby supporting the family economy. As you know, both are designed to permit care givers respite and an opportunity for relief from the "36-hour day" you referred to in your statement. These services allow care givers to get away, whether it is for a few hours or a few days, to attend personal needs or to simply get out from under the constant pressure.

We often speak of the high cost of caring to families. Existing Day Care programs range from modest volunteers run operations to costly day hospital programs. We need to know if the less costly activity-oriented programs might not become the programs of choice to help support families through their long course of caring.

Are there local agencies already in existence that would assist with supportive services?

Again, a number of states have begun to organize some support services. For the most part, however, this is still a community-based effort. Of course, the Administration on Aging has a network of state and local units that would provide support services. Unfortunately, their coverage of Alzheimer's patients has been somewhat uneven. For the most part this has been in the development of support groups. ADRDA would hope that this activity would be given over to the volunteers of ADRDA and efforts be re-directed to the development of respite care services for AD patients.

Your national agenda recommends a National Council on Alzheimer's Disease. What would such a Council do and why is it such an important part of an attack on Alzheimer's disease?

Senator, there are several reasons why an advisory council is important. To begin with, this is a national problem that requires a national effort. That means that some of the best talents and some of the brightest minds must be called in to help devise and carry out an attack on this problem.

Today, research scientists across the country are devoting their lives to finding the answer to this puzzle. But if we want to avoid unnecessary duplication and overlap, if we want to target research on the most promising areas of study, we need to have an overall plan of action. That means there has to be some degree of coordination--such as that provided by the National Cancer Advisory Board.

Beyond that, a National Council, such as you have proposed in S.2183, would draw together the top policy makers necessary

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to forge an efficient, responsive, and cost-effective long term care policy on Alzheimer's disease.

In your testimony you referred to the issue of federal disability benefits. Do you believe it would be advisable to update and disseminate information on Alzheimer's disease to disability examiners, and to train them adequately to understand the nature of th illness?

I certainly do. In fact, this is one of the high priority goals outlined in ADRDA's national program.

Although we don't have all of the answers, it is safe to say that science knows so much more about Alzheimer's than it did a decade ago. Why, then, should the rightful claims of patients be denied simply because state examiners do not have access to the latest information?

We have recommended that the Social Security Administration, working with the National Institutes of Health, develop a new set of criteria on the basis of Alzheimer's disease. At the same time, we suggest that claims examiners be given instruction on the nature of Alzheimer's disease.

Senator GRASSLEY. Ms. Gwyther.

Ms. GWYTHER. As a social worker, Mr. Chairman, I thank you for the opportunity to summarize what is known about innovative programs, methods, effectiveness, and cost.

Families providing care express strong feelings of responsibility, love and commitment. But watching a beloved parent succumb to a progressive deterioration of adult capacity, while providing greater levels of personal care, creates for even the most generous, heroic caregivers feelings of frustration, high levels of stress and fatigue and insufficient time for personal needs.

Thus, it appears that one of the serious consequences of Alzheimer's is its devastating effect on the health and well-being of the family caregiver.

Responsible policy must strengthen and supplement family efforts to provide care. We have ample evidence that formal services do strengthen and supplement willing family efforts to remain the major long-term care provider. However, families use many fewer services than are indicated or prescribed for them, and it should be clear that all innovative programs reach very few current dementia victims.

Alzheimer's disease is a unique illness because the patient's loss of adult judgment and reasoning makes him unable to be involved in decisions about his care. The decisions can become a point of major family conflict and increasing burden when family members have unequal access to information.

The care of Alzheimer's patients is uniquely difficult because they need more help with personal care, they are more likely to resist attempts to help, and they have unpredictable losses of impulse control. In spite of this, families respond valiantly.

Health services research has gone through several stages. First, we identified who the caregivers were—spouses, daughters and daughters-in-law.

Next, we looked at the effects on families of providing care for dementia victims. Most significant was the extreme variability among caregivers and patients and the lack of correlation between perceived burdens and the severity of the illness. Of equal significance were the pervasive effects on family emotional and mental health.

Our studies at Duke demonstrate family caregivers to be at risk of severe decrements in well-being, mental health, quality, and quantity of time available to meet personal needs. With an average of 5 years devoted to the care of one relative, there are significant effects on all members of a family.

The role of research on care is to learn how best to mitigate these potentially negative effects. The best way to strengthen family care may be to acknowledge the family caregiver as a legitimate recipient of services.

The bills currently before this subcommittee are most salient in their emphasis on care research—how best to provide timely, effectively dosed service options at a bearable cost. This is our hope for today and for all families on the front line.

Patients and families differ, and we need a range of service demonstrations, all of which are rigorously evaluated. This requires creativity and resources of all providers, who must be trained to

recognize and treat behavior changes as a symptom of illness and not a character flaw.

Excellent training materials do exist, but more are needed, and they need to be shared. Training of the provider offers the greatest security to families using existing services.

Specialized respite care programs are a demonstration of health services research. Respite is short-term substitute care for the victim on behalf and in the absence of the primary caregiver. The rationale is based on our understanding that as dementia progresses, supervision and personal safety needs preclude the patient's ability to remain alone. Respite is time off and relief to the primary family provider. It can be provided in the patient's own home, a day center, or an institutional setting. The direct recipient is the patient, but the primary beneficiary is the family. The probable benefits are, first, providing relief, which potentially reduces negative effects of caregiving upon well—being, and second, improving caregiver effectiveness by enabling the respite workers to share useful strategies with the families.

Although a strong intuitive case can be made for the value of respite, there has been no rigorous evaluation of the impact of this service. No one knows the most effective models for targeting and delivering respite, or the extent to which such programs reduce caregiver burden or enhance caregiver effectiveness.

Our current AARP-funded research is one attempt to answer this question. Preliminary findings indicate that the biggest initial barriers to use of in-home respite are the cost and the difficulty in reaching the family caregiver at the time of greatest need. Many families do not trust strangers, and many are too isolated, or guilty, to leave their relatives. By the time they request service, they need a combination of services more intensive than they can afford or voluntary services can provide.

Can we demonstrate that a specific program like in-home respite reduces the level of burden and extends family capacity to provide this invaluable personal care? This is a question that must be answered before public and private sector can make accurate estimates of potential demand and cost. Other service options deserve similar close scrutiny.

I would like to close with the response of consumers to our efforts. The following excerpt is from a letter written by a 67-year-old woman who has been caring for her demented husband 4 years and is now receiving 8 hours a week of respite care.

She says:

> Many of us believe no one can help, and that is not true. Now I do more things like I used to. I know Clark is in good hands, and Annie always takes him for a walk or does something else good with him. I only wish I could have more of this. I think I could be a better person and take better care of Clark that way. We just could not save enough to afford that kind of help. We raised three children and did not have much schooling, but we always paid plenty of taxes.
>
> I do not mean to complain. Your caring is wonderful. Please do not stop.

I can only add my plea to that of this caregiver: Thank you for caring, and please do not stop.

Senator GRASSLEY. Thank you.

[The prepared statement of Ms. Gwyther and responses to questions submitted by Senators Grassley and Metzenbaum follow:]

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HEARING TESTIMONY
July 22, 1986
U.S. SENATE SUBCOMMITTEE ON AGING
CARE OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

INNOVATIVE PROGRAMS: WHAT DO WE KNOW ABOUT METHODS, EFFECTIVENESS AND COST?

Families have provided and will continue to provide the majority of long-term care services to their relatives with Alzheimer's (AD) or related disorders. Research indicates the effects of providing this care on family capacity to meet multiple obligations threatens to become a significant health care issue of its own. Families providing care for confused older relatives express strong feelings of responsibility, love and committment; however, watching a beloved parent or spouse succumb to progressive deterioration of adult capacities while providing greater levels of personal care creates, for even the most generous, capable and heroic caregivers, feelings of frustration, high levels of stress and fatigue, and insufficient time for personal needs. Thus, it appears that one of the serious consequences of AD and related disorders is its devastating effects upon the health and well-being of the family caregiver. This has become a major social policy issue which is unfortunately clouded by myths and significant gaps in information. Responsible policy, such as that proposed in the bills before this Subcommittee, must strengthen and supplement family efforts to provide care for relatives with

dementing illness.

A shrinking number of available family caregivers are providing more difficult care for more dementia victims than in any previous time in our history. Older people with any chronic illnesses value their family's emotional support and dependability in time of need more than any other long term care service. We have ample evidence that formal services strengthen and supplement a willing family's efforts to remain as the major provider of long term care. There are no known incentives to encourage unwilling or incapable families to provide care, just as there are no known disincentives which discourage willing families from their commitment and responsibility to beloved relatives.

Demographers remind us that most of us will be called upon to help provide parent care. Half of current middle aged couples have more than <u>two</u> surviving parents. Families invented long-term care as an issue distinct from acute episodic care long before it came to the attention of government or professionals.

A recent national survey documents that the mostseverely disabled elders in obvious need of formal services are rarely helped by the formal service system. It is the experience of my colleagues that families of dementia patients use many fewer services than are indicated or prescribed for them. Therefore, it should be clear that all current innovative programs reach very few dementia victims. Most dementia victims live in the community unknown to any providers.

When families do place a relative in a nursing home, research indicates they have exhausted all physical, emotional and often financial resources trying to avoid what is acknowledged as the most stressful decision a family caregiver must face. Duke's AARP-funded

Alzheimer's research indicates that most families use no formal services until the year before placement, at which time, enormous amounts of usually unavailable services are needed in crisis. The most stressed group of caregivers of dementia victims are those immediately preceeding and immediately post institutional placement of a relative. Placement offers no relief from the emotional responsibility of care, and therefore facilities offering innovative care must be prepared to care for the family as well as the AD patient.

AD is unique in that the patient can't be involved, because of loss of adult judgement and reasoning, in decisions about his/her care. These decisions can become a point of major family conflict and increasing burden when family members have unequal access to reliable information about the disease, their relative's functional capacity, and prognosis. The care of AD patients in middle to later stages is uniquely difficult because they need more help with personal care assistance, they are more likely to resist well-meaning attempts to help, and they have unpredictable losses of impulse control that may subject their often-frail spouse/caregiver to verbal and/or physical abuse. In spite of all this, families respond valiantly, and heroism among surviving family caregivers is much more common than defeat.

Health services research related to AD care has gone through several stages. First, we identified who was providing care - spouses first, daughters second, and daughter-in-laws, third. While most care providers are women, Alzheimer's has forced researchers to discover some unique aspects of caregiver burden among husbands as a major care provider group. Next, researchers began to study the effects on families of providing care for dementia victims. Most significant were findings of extreme variability among both caregivers and

patients, and the lack of correlations between perceived burden and the severity of the patient's illness. Of equal significance are the pervasive effects of providing care on family emotional and mental health. AARP- funded studies at Duke clearly demonstrated family caregivers to be at risk of serious decrements in well-being, mental health and quality and quantity of time available to meet personal needs. Caregivers are now commonly referred to as the secondary victims of Alzheimer's Disease, a costly, unintended consequence of our societal reliance on family care. We found Alzheimer's caregivers using 4 times as much psychoactive drugs and alcohol to cope than age matched community samples. Our average caregiver was 60 years old, often with many competing career, family and personal responsibilities and often chronic impairments of his/her own. With an average of 5 years devoted to the care of one relative, there are significant effects on all members of a family and on family lifestyle.

We now know that the well-being of all generations within a family is interlocked. We can't encourage families to do any more than they are currently doing. The innovative programs in respite, day centers and income supports for caregivers could be important models or prototypes for a societal policy indicating commitment to families of all ages. Families will continue to be personally devastated by the slow loss to a dementing illness of a competent relative, and they will continue to do their best to enhance the quality of care for these relatives. The role of research on care is to learn how best to mitigate the potentially irreversible effects on second and third victims of dementia. The best way to strengthen family care is to strengthen formal services acknowledging family caregivers as

legitimate recipients of service in their own right.

The thrust of the bills currently before this Subcommittee is to develop effective partnerships in research to enhance quality of life, cost effectiveness and financing of programs for Alzheimer's and related disorders patients. The most salient aspect of these bills is the emphasis on care research - how best to provide timely, effectively-dosed service options at a bearable cost. Biomedical and laboratory research is our hope for future prevention and cure. Health services research is our hope for today and for all families currently on the front lines in providing care. We know more today about the special skills required to provide respite, day or institutional care for dementia victims. We know families will continue to be reluctant to pay for or use these services until they are assured that training in state-of-the-art care is regularly available to all levels of direct care providers. Currently, services are unevenly available, of uneven quality and in generally scant supply. Many potential users of services don't know about them, and even with knowledge of available services, many find barriers to their personal use - red tape, multiple providers necessitated by an arbitrary division of health and social support services and reimbursement policies, and inadequate training of direct care staff, whose high turnover rates require repeated efforts at training.

Patients and families differ so much that we must develop a range of service demonstrations, all of which are rigorously evaluated. This requires the creativity and resources of all providers but especially those represented in S2183 - the Veteran's Administration, ADRDA, and the non-profit and public sectors, including our state institutions. Day center, respite, institutional and safety personnel must be trained

in requisite skills to treat behavior changes of AD patients as a symptom of illness, and not as a character flaw. Health services research may point out how best to encourage families to use the formal system in a more timely, appropriate manner or how to provide services for such a potentially long-term illness at a bearable cost to both families and society. We need more rigorous documentation of appropriate auspices, settings, staffing and costs of alternative programs. The problem of dementia care, even at current levels, is too costly to be assumed by any single group. The Institute of Medicine Report on Quality of Care in Nursing Homes highlights the special problems with equity, access and quality of care for dementia victims. The proposed changes in survey mechanisms are attempts to assess quality of care and quality of life issues that form the basis of health services research. All levels of long-term care providers must be taught the importance of thorough evaluation and frequent reassessment of function, abilities and disabilities, along with regular assessment of potential excess disabilities, more amenable to treatment.

Excellent training materials and curricula exist, but more are needed. Most important, there must be mechanisms to share existing training materials. Training of providers offers the greatest security to families in using existing services. Family caregivers are often willing to assume care responsibilities and eager to learn ways to care more effectively. But special outreach and training is necessary to reach those most open to learning at their point of greatest personal need.

Health services research tries to answer this question: Can we

demonstrate convincingly positive results from an intuitively good service idea at a bearable cost? Increasingly, special care programs offering in-home respite, day center, or special care activities or environments within nursing homes are springing up in response to consumer demand and dissatisfaction with the capacity of current services to meet the unique needs of AD patients and their families. Specialized dementia respite care programs are just one such example.

Respite has been identified in many research studies of dementia families as the most necessary and least available service. Respite is short term, intermittent substitute care for the dementia victim on behalf and in the absence of the primary care provider. The rationale for this type of service is based on our understanding that as dementia progresses, supervision and personal safety needs preclude the patient's ability to remain alone. Respite offers scheduled time off and a period of relief for the family care provider to meet personal needs. Respite could be provided in the patient's own home, a day center or a residential/institutional setting offering overnight care. The direct recipient of service is the dementia patient, but the primary beneficiary is the family caregiver.

The probable benefits of respite care are first, providing relief to caregivers, which potentially reduces the negative effects of caregiving upon well-being; and second, improving caregiver effectiveness, either by reducing burden or by enabling respite workers to share useful strategies with the family, thus extending the caregiver's ability to provide home based care.

However, although a strong intuitive case can be made for the value and benefits of respite care, there has as yet been no rigorous evaluation of the impact of respite care. Although it's an attractive

service option, no one knows the most effective models for targeting and delivering respite, or the extent to which such programs can reduce caregiver burden or enhance caregiver effectiveness. Our current AARP-funded Duke research demonstration is one such attempt to answer these questions.

Preliminary findings from our Duke Respite demonstration which offers companion/sitter services in the patient's own home, indicate that the biggest initial barriers to use of formal respite service are the cost and the difficulty in reaching the family caregiver at the time of greatest need. Most families cannot afford the cost of a supervised and trained in-home aide, yet they are above financial eligibility for Medicaid waiver programs. Subsidies of some sort are essential, yet most families want to contribute something in order to maintain control. Many families don't trust strangers to provide personal care, and many are too isolated or guilty about leaving their relative to venture out in the community. By the time they request service, they need a combination of skilled nursing and companion services, which is more intensive service than they or private sources can afford.

We must also rigorously evaluate the impact of respite services on caregiver burden. Can we demonstrate that a specific program like respite reduces the level of burden for a previously over-burdened caregiver, and extends family capacity to continue providing this invaluable personalized care? This is a question which must be answered by health services research before we can give the public and private sectors accurate estimates of potential demand, cost and mechanisms for sharing the cost of these services. Other service

options deserve similar close scrutiny and evaluation. The impact of respite care cannot be properly assessed except within the larger context of a range of community and institutionally based family support services.

Special care units in nursing homes are another innovation, and families and state regulatory agencies are demanding guidelines to evaluate these programs, or minimum standards upon which to insist before offering reimbursement. None of this is possible given current understanding of what works and how best to provide quality care at a bearable cost. For this reason, "special" and probably "superior care" is available unevenly and only to those with active family advocates who can afford to pay privately. The bills before you address Medicaid discrimination in nursing home access, but access to all special and enriched care programs are now equally discriminatory.

Program developers and researchers are keenly aware that we need to try out more creative ideas before making decisions about reasonable care options and potential funding, or before setting minimum standards for any special program. Health services research will help us adapt what works from these evaluated innovative approaches to our current resources. This will offer useful, immediately relevant answers for the present and the forseeable future.

We probably can't go wrong in program innovations as long as we acknowledge that no single setting or single helping strategy will provide total relief for such a heterogenous population. "Best care" awaits knowing how much amelioration is possible, for which patients, with which levels of family support, at which points in this disabling illness.

We do know that any innovative, affordable and appropriate

programs must combine medical and social support services with simplified reimbursement mechanisms. Specialized care of any type, at a minimum, negates current pessimism about what can be done for both patients and families. Finally, specially designed programs and settings could benefit patients with other disabilities, so innovations in AD care will never be helping one chronic illness at the expense of another. All special care is at least an attempt to redesign care to fit the patient, rather than the reverse, and the demands for "special anything" helps us re-frame problems into solvable challenges. With increasing confidence in our rigorously controlled and evaluated program demonstrations, families will be more secure in entrusting their relatives to our care. Special care programs can then become places where something is being done toward some mutually agreeable end, rather than just programs with higher price tags.

In the meantime, it's helpful to focus on the response of consumers to our efforts. The following excerpt is from a letter written by a 67 year old woman who has been caring for her demented husband for nearly four years. She now is receiving respite care services eight hours a week from our Duke respite demonstration.

Many of us believe that no one can help at all and that is not true. Now I do more things like I used to. I know Clark is in good hands and Annie always takes him for a walk on a pretty day or finds other good things for him to do. I only wish I could have more of this. I think I could be a better person and take better care of Clark that way. We just couldn't save enough to afford that kind of help. We raised three children and did not have much schooling. But we always paid plenty of taxes. I do not mean to complain. Your caring is wonderful. Please don't stop.

I can only add my plea to that of this caregiver. Thank you for caring and please don't stop.

LISA GWYTHER

IF YOU WERE TO LIST IN PRIORITY ORDER THE THREE OR FOUR THINGS MOST NEEDED BY FAMILIES WHICH CARE FOR ALZHEIMER'S DISEASE VICTIMS, WHAT WOULD THEY BE?

First, families must have access to current reliable information on the disease, services available and their relative's condition. This information must be interpreted in understandable terms to all responsible family members at a time and in doses which can be absorbed. Second, families need access to reliable primary medical care for the duration of the illness. Third, families need a range of acceptable, affordable and high quality respite options whether they be residential, day care or in-home respite care. The providers of any respite services must be specially trained to handle the behavioral and communication problems of dementia victims. Finally, families need affordable accessible, high quality long term care options in facilities which range from board-and-care through super skilled nursing facilities and hospitals.

WHICH WOULD BE THE MOST EXPENSIVE OF THOSE, AND DO YOU HAVE ANY WAY OF ESTIMATING HOW MUCH EACH WOULD COST?

Obviously, long-term skilled institutional care is very costly, and skilled help at home can be equally or more costly without the attendant economies of scale available in long-term care facilities. The problem with estimating cost is that it is so difficult to predict demand. We know people use very few formal services, and many families wait until the intensity of service needs is too great for the available resources. We have estimates of current costs from several studies, but they are limited to a specific time within the framework of a long-term illness. Many service needs are not predicated on the patient's condition or symptoms, but rather by the availability of informal or family assistance. Any additional services covered by third party payers will obviously add costs for the short term, but timely low-cost services could save more in delaying use of more expensive services for the long term. It's difficult to predict costs of caring for an AD victim, because many AD victims are older and may have concurrent chronic illnesses which will add costs to their care. Information is the least expensive service. ADRDA as an national voluntary health organization offers public/community education to an extent impossible to achieve by any single federal agency. However, provider education is critically and equally important. It requires a greater share from federal sources.

QUESTIONS FOR LISA GWYTHER FROM SENATOR METZENBAUM REGARDING ALZHEIMER'S DISEASE

COORDINATION

DO YOU BELIEVE IT WOULD BE HELPFUL TO HAVE A NATIONAL COORDINATED EFFORT IN PLACE TO PROVIDE INFORMATION, GUIDANCE AND TECHNICAL ASSISTANCE AND TO FACILITATE THE DEVELOPMENT OF NEW STRATEGIES? WHO SHOULD PARTICIPATE IN SUCH AN EFFORT?

Coordination of information dissemination and technical assistance is imperative at all levels. I direct a state-funded information and technical assistance facility which saves our state's ADRDA chapters time and expense by providing immediate access to expert knowledge to supplement and enhance voluntary efforts. On the federal level, participants should include ADRDA, all relevant institutes of NIH (NIA, NINCDS), HHS, AoA, HCFA, NIMH, and NCHSR. In addition, the national nursing home associations (AAHA, AHCA), and the national aging associations (GSA, ASA, AGS, NCOA) shoUld be represented. Because provider education is so important, some representation is needed from all major national organizations of health and social service professionals as well.

REGISTRY

WOULD A REGISTRY FOR REFERRALS TO HEALTH CARE PROFESSIONALS BE HELPFUL TO FAMILIES?

It is probably wiser to have families go through local consumer organizations such as ADRDA for referrals to professionals. The NIA ADRC's could also assist with referrals. We must keep in mind that the best health providers may be interested generalists in primary care. While specialists may be necessary for diagnostic evaluation, many states are organizing to provide regional diagnostic services. Once diagnosis and treatment recommendations are confirmed, local primary care becomes essential for patient management and assistance to family caregivers. ADRDA chapters and support groups are in the best position to provide such information.

DAY CARE AND RESPITE CARE

ARE MORE FACILITIES FOR DAY CARE AND RESPITE CARE NEEDED? HOW CAN THE FEDERAL GOVERNMENT ASSIST NON-PROFIT AGENCIES WITH THE DEVELOPMENT OF SUCH FACILITIES?

Day care and respite care options currently serve a minority of dementia patients in need of such services. These services are unevenly distributed, and they are often regionally unavailable in rural areas. The federal government could assist with start-up costs and financial incentives for non-profits to take risks in developing such services. This should be a coordinated effort with ADRDA to assure adequate, rigorously evaluated demonstrations to determine which service models

QUESTIONS FOR LISA GWYTHER FROM SENATOR METZENBAUM REGARDING ALZHEIMER'S DISEASE

DAY CARE AND RESPITE CARE (CONT'D)

are most acceptable and appropriate at a bearable cost. These demonstrations are vital in projecting future demand and distribution. An important federal role then becomes sharing these data with non-profits interested in developing respite and day care options. Federal support for training and dissemination of training materials for providers further assures consumer trust in using these services.

EDUCATION

WHERE SHOULD EDUCATIONAL EFFORTS BE CONCENTRATED? CLINICAL CARE PROVIDERS? HOME HEALTH AIDES? NURSING HOME PERSONNEL? POLICE AND BUS DRIVERS? CORONERS?

The first priority in educational efforts has to be the education of hands-on providers. This includes physicians, all allied health providers, but especially those hands-on providers known to have the greatest impact on quality of care and quality of life - home health aides and nursing home aides. Aides spend the greatest number of direct contact hours with patients and families. These paraprofessionals have the least access to professional training, collegial sharing, career ladders, and they have the highest turnover rates. Therefore, education of providers must be an on-going process. Families of dementia patients also place high priority on education of pathologists. There are a limited number of pathologists willing or trained to provide autopsy confirmation of the diagnosis. As we learn more about the genetics of dementing illness, it becomes more imperative to have specific confirmation of diagnosis for genetic counseling purposes. Emergency personnel on all levels also must be trained to handle inevitable crises with dementia patients. This, however, can be a shared responsibility of the public, private and voluntary sectors.

CONTINUUM OF CARE

CAN HEALTH SERVICES RESEARCH POINT TO STRATEGIES FOR DEVELOPING A CONTINUUM OF CARE FOR EACH PATIENT?

Yes. The variability among patients and families demands a range of care options throughout the course of the illness. Health services research can lead to predictors for which service models must be necessary for how long at specific projected costs. Health services research may further help target services to encourage more timely, cost-effective use over the course of such a long-term illness. Better estimates of the risk of dementing illness will also help us project costs of care and potential demand for specific services or insurance. Better designed and monitored care delivery systems could be developed to specifically address the prominent behavioral symptoms and the labor-intensive personal care needs of all dementia patients.

Senator GRASSLEY. Commissioner Sainer.

Ms. SAINER. Thank you. I am Janet Sainer, commissioner of the New York City Department for the Aging, which is both an arm of municipal government and the largest area agency on aging in the Nation.

I will skip the appreciative remarks as you suggested, Senator, and go on with the abbreviated statement of my text.

In 1984, the New York City Department for the Aging established the New York City Alzheimer's Resource Center. It was the first municipally sponsored agency of its kind in the Nation and is funded by the Brookdale Foundation and the city of New York.

Today, with our 2½ years of experience, we can reconfirm our view that the care of people with Alzheimer's disease must include the care of people whose lives are affected by Alzheimer's disease—namely, the families of the Alzheimer's victims.

Families have taught us how desperately enmeshed they are in the dilemma of increasing demands and decreasing resources—financial, emotional, and physical. Jerry Stone has spoken eloquently on many occasions to this point.

Thus, the New York City Alzheimer's Resource Center, which was established in collaboration with the New York City chapter of ADRDA, began its task of providing guidance, and information and services to Alzheimer's families and professionals.

Most recently the center was funded by the Administration on Aging as one of its 12 national Alzheimer's disease initiative demonstration projects, to implement legal and financial planning services, which we found to be a critical issue, particularly for those who could not otherwise afford private counsel.

Without question, I believe that the aging network—the area agencies on aging and the State units on aging—are in a unique position to respond, together with others, to the special needs of this very special population. As a result of the implementation of The Older Americans Act this network is administering a variety of community-based services, has expertise in entitlements for which Alzheimer's patients and families may qualify, and has the capacity and ability to link those in need to other service systems. Most importantly, it has the administrative structure in place that can be built upon in a most cost-effective fashion to meet the demands of the overburdened Alzheimer family population.

The New York City Alzheimer's Resource Center, in a joint venture with the Brookdale Foundation, recently initiated a nationwide survey of Alzheimer's-related activities currently being conducted by State units and area agencies on aging. This 164 page book, listing the programs in every State in which the area aging network is involved, will be ready for distribution in August.

It is clear from what we have found that the aging network is mobilizing to meet the challenge of Alzheimer's disease and related disorders. I will not attempt any indepth review of what we found. However, there are three significant trends.

First, 17 States have created Alzheimer's task forces or study commissions and convened statewide conferences to investigate the impact of Alzheimer's disease and to make recommendations for appropriate State action. Thirteen States have either passed specif-

ic legislation or have appropriated funds for Alzheimer's related efforts.

Second, at the area agency level, all AAA's reported that they include Alzheimer's victims among the frail elderly population for whom they provide basic services, but many are also targeting services specifically for the specific needs of Alzheimer's families.

Third, we found that the network has engaged extensively in collaborative programs and is working closely with a variety of groups ranging from the Alzheimer's Disease and Related Disorders Association to philanthropic foundations, police departments, American Red Cross, private industry, churches, universities, gerontology centers, and mental health and social service agencies.

In addition, a number of area agencies are conducting joint activities with local ADRDA affiliates. Many area agencies on aging are providing ADRDA groups with some limited financial support to underwrite various administrative costs, to staff and enhance family support groups, and in some cases to help establish a new local ADRDA chapter.

The aging network has also sponsored, underwritten, led or designed a number of innovative approaches to meet the needs of Alzheimer's families.

In your own State of Iowa, Mr. Chairman, the University of Kansas and the AOA regional office are promoting a cooperative approach to information dissemination on Alzheimer's and the development of family support groups in rural areas.

The State of Ohio has passed legislation that would aid victims of Alzheimer's disease in a host of very important ways.

What is clear, however, is that despite the measures underway to meet these ever-mounting needs, many of these are time-limited, demonstration projects. It is our hope that your legislation, and the various bills, will make more of what is needed possible.

I want to assure you that we endorse fully support for expanded research in the whole area of Alzheimer's disease. I am also particularly pleased to note that in a number of bills, special consideration is given to enhancing service to family caregivers. We strongly endorse the utilization of the aging network's expertise and service capability. This was particularly noted in the bills proposed by Senator Metzenbaum, and we were very pleased to note the amendments proposed to The Older Americans Act in that bill.

We were also pleased, as Mr. Stone mentioned, to see the recommendation to update the disability guidelines of Social Security to include Alzheimer's disease as one of the designated illnesses for disability allowance.

Senator Pressler's bill we found had some very important comprehensive programmatic concepts. However, we would hope that the activities that are designated in that bill would not be limited solely to the Public Health Service, as important as that organization is, but that there would be a defined linkage between the Public Health Service and the Administration on Aging.

I have just read a draft copy of the committee's bill, and I want to compliment you for the emphasis on service-relevant research. However, in a very quick reading, I was surprised to note the absence of any role for the Administration on Aging and its vast network of State and local units on aging. May I be so bold as to sug-

gest a role, and that is to expand the service demonstration capability of AOA—not necessarily the research capability—so that the research worked on by the three organizations proposed would have an enhanced data base.

Senator GRASSLEY. I think I had better ask you to quit.

Ms. SAINER. OK.

[The prepared statement of Ms. Sainer follows:]

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JANET S. SAINER, Commissioner

TESTIMONY

CARE OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

presented by

JANET S. SAINER, COMMISSIONER

NEW YORK CITY DEPARTMENT FOR THE AGING

before the

UNITED STATES SENATE
COMMITTEE ON LABOR AND HUMAN RESOURCES
SUBCOMMITTEE ON AGING

HON. CHARLES E. GRASSLEY
CHAIRMAN

JULY 22, 1986

DIRKSEN SENATE OFFICE BUILDING
WASHINGTON, DC

I AM JANET SAINER, COMMISSIONER OF THE NEW YORK CITY DEPARTMENT FOR THE AGING, WHICH IS BOTH AN ARM OF MUNICIPAL GOVERNMENT AND THE LARGEST AREA AGENCY ON AGING IN THE NATION. OUR DEPARTMENT ACTS AS AN ADVOCATE FOR MORE THAN 1.3 MILLION NEW YORKERS 60 YEARS OF AGE AND OLDER.

I GREATLY APPRECIATE THE OPPORTUNITY TO TESTIFY TODAY ON A MATTER OF MOUNTING NATIONAL CONCERN AND CONSEQUENCE:"THE CARE OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS...".

IN 1984, THE NEW YORK CITY DEPARTMENT FOR THE AGING ESTABLISHED THE NEW YORK CITY ALZHEIMER'S RESOURCE CENTER. IT WAS THE FIRST MUNICIPALLY-SPONSORED AGENCY OF ITS KIND IN THE NATION AND IS FUNDED BY THE BROOKDALE FOUNDATION AND THE CITY OF NEW YORK. TODAY, WITH OUR TWO AND HALF YEARS OF EXPERIENCE, WE CAN RECONFIRM OUR VIEW THAT THE CARE OF PEOPLE WITH ALZHEIMER'S MUST INCLUDE THE CARE OF PEOPLE WHOSE LIVES ARE AFFECTED BY ALZHEIMER"S DISEASE -- NAMELY, THE FAMILIES OF ALZHEIMER'S VICTIMS.

FAMILIES HAVE TAUGHT US HOW DESPERATELY ENMESHED THEY ARE IN THE DILEMMA OF INCREASING DEMANDS AND DECREASING RESOURCES--FINANCIAL, EMOTIONAL AND PHYSICAL. WE HAVE SEEN FIRST-HAND HOW THE PROGRESSIVE DETERIORATION AND UNPREDICTABILITY OF THE DISEASE FORCE THE PATIENT AND FAMILY TO ADJUST CONTINUOUSLY TO NEW AND HIGHER LEVELS OF IMPAIRMENT. WITH THESE EVER-CHANGING LEVELS COME NEW AND DIVERSE NEEDS THAT MUST BE MET. THIS IS A COMPELLING CHALLENGE FOR THE AGING NETWORK LONG ACCUSTOMED, AND ADEPT AT, RESPONDING TO THE DEMANDS OF A CHANGING OLDER POPULATION.

THUS, THE NEW YORK CITY ALZHEIMER'S RESOURCE CENTER, WORKING IN COLLABORATION WITH THE NEW YORK CITY CHAPTER OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, BEGAN ITS TASK OF PROVIDING GUIDANCE AND INFORMATION TO ALZHEIMER'S FAMILIES AND PROFESSIONALS ON AVAILABLE SERVICES AND PROGRAMS, APPROPRIATE MEDICAL DIAGNOSTIC CENTERS, BENEFITS AND ENTITLEMENTS, REIMBURSE-

MENT ISSUES, LEGAL AND FINANCIAL CONCERNS, IN-HOME SERVICES, INSTITUTIONAL PLACEMENT... AND RESOURCES DESIGNATED TO HELP MAINTAIN THE PATIENT IN THE COMMUNITY SUCH AS ADULT DAY CARE, RESPITE, HOME DELIVERED MEALS, HOME SERVICES AND FRIENDLY VISITING.

THE CENTER'S GROWTH HAS BEEN EVOLUTIONARY IN NATURE. WE HAVE RESPONDED TO EMERGING NEEDS, IDENTIFIED SERVICE GAPS AND SOUGHT TO ADAPT EXISTING SERVICES AND PROGRAMS TO MEET THE SPECIALIZED DEMANDS THAT THIS DISEASE CREATES. THE CENTER PROVIDES FREE ONE-ON-ONE COUNSELING FOR FAMILY MEMBERS WHO NEED SHORT-TERM CRISIS INTERVENTION. WE HAVE CONVENED AND LED SEMINARS AND WORKSHOPS FOR SPECIAL TARGET GROUPS SUCH AS HOUSING AUTHORITY PERSONNEL, PRECINCT POLICE, AND THE CLERGY. WE HAVE HELD ANNUAL MAYORAL CONFERENCES BOTH TO RAISE THE AWARENESS LEVEL OF THE PUBLIC AT LARGE AND TO PROVIDE AN ARENA IN WHICH FAMILY CAREGIVERS AND PROFESSIONALS CAN SHARE THEIR POINTS OF VIEW, THEIR KNOWLEDGE AND THEIR WISDOM ON HOW ALZHEIMER'S-RELATED NEEDS MAY BE ADDRESSED.

RECENTLY, THE CENTER WAS FUNDED BY THE ADMINISTRATION ON AGING AS ONE OF ITS TWELVE NATIONAL ALZHEIMER'S DISEASE INITIATIVE DEMONSTRATION PROJECTS TO IMPLEMENT LEGAL AND FINANCIAL PLANNING SERVICES FOR ALZHEIMER'S FAMILIES WHO CANNOT OTHERWISE AFFORD PRIVATE COUNSEL. THE CENTER NOW HAS A PROFESSIONALLY TRAINED AND SUPERVISED CORE OF LAW INTERNS WHO PROVIDE ASSISTANCE IN AREAS OF POWER OF ATTORNEY, ESTATE PLANNING, FAIR HEARINGS, PUBLIC BENEFITS, AND MATTERS RELEVANT TO LONG-TERM CARE OF ALZHEIMER'S PATIENTS.

RESEARCH INDICATES THAT MOST FAMILIES KEEP THEIR RELATIVES AT HOME FOR 4 TO 7 YEARS OR MORE AFTER THE DIAGNOSIS HAS BEEN MADE. THESE CAREGIVERS NEED INCREASING HELP IN MANAGING THE CARE OF THE PATIENT AT HOME AND IN COPING WITH THE RIGORS OF WHAT HAS BEEN SO APTLY CALLED "THE 36-HOUR DAY." A SADLY DISTINGUISHING FEATURE OF ALZHEIMER'S DISEASE IS THAT IT NORMALLY

FOLLOWS A LENGTHY COURSE OF DECLINE AND THAT ITS CONTINUUM IS STAGGERING BOTH IN THE INTENSITY OF CARE NEEDS AND THE TOLL IT TAKES ON THE FAMILY CAREGIVER.

WITHOUT QUESTION, THE AGING NETWORK IS IN A UNIQUE POSITION TO RESPOND TO THE SPECIAL NEEDS OF THIS VERY SPECIAL POPULATION. WITH THE IMPLEMENTATION OF THE OLDER AMERICANS ACT AND THE DEVELOPMENT OF STATE OFFICES ON AGING AND THE 672 AREA AGENCIES ON AGING, THIS NETWORK IS ADMINISTERING A VARIETY OF COMMUNITY BASED SERVICES, HAS EXPERTISE IN ENTITLEMENTS AND HAS THE CAPACITY AND ABILITY TO LINK THOSE IN NEED TO OTHER SERVICE SYSTEMS. MOST IMPORTANTLY, IT HAS THE ADMINISTRATIVE STRUCTURE IN PLACE THAT CAN BE BUILT UPON IN A MOST COST EFFECTIVE FASHION TO MEET THE DEMANDS OF THE OVERBURDENED ALZHEIMER'S FAMILY POPULATION.

THE NEW YORK CITY ALZHEIMER'S RESOURCE CENTER, IN A JOINT VENTURE WITH THE BROOKDALE FOUNDATION, RECENTLY INITIATED A NATIONWIDE SURVEY OF ALZHEIMER'S-RELATED ACTIVITIES CURRENTLY BEING CONDUCTED BY STATE UNITS AND AREA AGENCIES ON AGING. OUR CENTER SOUGHT TO GAIN INSIGHT AND KNOWLEDGE FROM OTHER NETWORK AGENCIES WORKING ON BEHALF OF ALZHEIMER'S VICTIMS, AND TO SHARE THIS COLLECTED INFORMATION AND WISDOM WITH ALL THOSE CONCERNED WITH THE PROBLEM. THE RESULT OF THE SURVEY IS A 200-PAGE REFERENCE BOOK CALLED, AGENDAS FOR ACTION: THE AGING NETWORK RESPONDS TO ALZHEIMER'S DISEASE. IT HIGHLIGHTS THE ACTIVITIES OF THE AGING NETWORK AND ITS COLLABORATIVE EFFORTS ON BEHALF OF ALZHEIMER'S PATIENTS. "AGENDAS FOR ACTION" WILL BE READY FOR DISTRIBUTION NEXT MONTH.

THE RESULTS OF THIS STUDY ARE ENLIGHTENING AND ENCOURAGING. IT IS CLEAR THAT THE AGING NETWORK IS MOBILIZING TO MEET THE CHALLENGE OF ALZHEIMER'S DISEASE AND RELATED DISORDERS. AND IT IS DOING SO IN COOPERATION WITH OTHER COMMUNITY ORGANIZATIONS IN A TRUE SENSE OF DEDICATION AND COMMITMENT

AND WITH REMARKABLE INGENUITY AND RESOURCEFULNESS.

WHILE I WILL NOT NOW ATTEMPT AN IN-DEPTH REVIEW OF THE FINDINGS OF THIS SURVEY, I WOULD LIKE TO POINT TO THREE OF ITS MOST SIGNIFICANT TRENDS.

1...17 STATES HAVE CREATED ALZHEIMER'S TASK FORCES OR STUDY COMMISSIONS AND CONVENED STATEWIDE CONFERENCES TO INVESTIGATE THE IMPACT OF ALZHEIMER'S AND TO MAKE RECOMMENDATIONS FOR APPROPRIATE STATE ACTION..13 STATES HAVE EITHER PASSED SPECIFIC LEGISLATION AND/OR APPROPRIATED FUNDS FOR ALZHEIMER'S-RELATED EFFORTS.

2...AT THE AREA AGENCY ON AGING LEVEL, ALL AAAs REPORTED THAT THEY INCLUDE ALZHEIMER'S VICTIMS AMONG THE FRAIL ELDERLY POPULATION FOR WHOM THEY PROVIDE BASIC SERVICES; MANY ARE ALSO TARGETING SERVICES TO THE SPECIFIC NEEDS OF ALZHEIMER'S FAMILIES. THESE SERVICES INCLUDE: SPECIAL IN-HOME SERVICES AND OTHER RESPITE CARE PROGRAMS; THE DEVELOPMENT OF FAMILY SUPPORT GROUPS INDEPENDENTLY OR TOGETHER WITH ADRDA OR OTHER COMMUNITY ORGANIZATIONS; AND THE INITIATION OF ADULT DAY CARE FOR ALZHEIMER'S PATIENTS.

3...IN ITS ROLE AS A COORDINATING AGENCY, IT IS SIGNIFICANT THAT THE NETWORK HAS ENGAGED EXTENSIVELY IN COLLABORATIVE PROGRAMS. IT IS WORKING CLOSELY WITH A VARIETY OF GROUPS, RANGING FROM THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION TO PHILANTHROPIC FOUNDATIONS, POLICE DEPARTMENTS, AMERICAN RED CROSS, PRIVATE INDUSTRY, CHURCHES, UNIVERSITIES, GERONTOLOGY CENTERS AND MENTAL HEALTH AND SOCIAL SERVICE AGENCIES.

IN ADDITION,A NUMBER OF AREA AGENCIES ON AGING ARE CONDUCTING JOINT ACTIVITIES WITH LOCAL ADRDA AFFILIATES. MANY AREA AGENCIES ON AGING ARE PROVIDING ADRDA GROUPS WITH FINANCIAL SUPPORT TO UNDERWRITE VARIOUS ADMINISTRATIVE COST, TO STAFF AND ENHANCE FAMILY SUPPORT GROUPS,AND IN SOME CASES TO HELP ESTABLISH A NEW LOCAL ADRDA CHAPTER.

THE AGING NETWORK HAS ALSO SPONSORED, UNDERWRITTEN, LED OR DESIGNED A NUMBER OF INNOVATIVE APPROACHES TO MEET THE NEEDS OF ALZHEIMER'S FAMILIES. FOR EXAMPLE:

...IN THE STATE OF MAINE, THE BUREAU OF MAINE'S ELDERLY IS BUILDING A SPECIALLY DESIGNED BOARDING HOME TO HOUSE UP TO 30 ALZHEIMER'S PATIENTS FOR SHORT-TERM RESPITE CARE.

...THROUGH THE CONNECTICUT STATE DEPARTMENT FOR THE AGING, THREE VOLUNTARY AGENCIES ARE RECRUITING AND TRAINING 100 VOLUNTEERS AS SPECIAL AIDES TO ALZHEIMER'S PATIENTS IN THEIR HOMES.

...TWO AREA AGENCIES IN PENNSYLVANIA ARE DEVELOPING A TRAINING PROGRAM WITH THE PRIVATE INDUSTRY COUNCIL UTILIZING TITLE V OLDER WORKERS TO TAKE CARE OF ALZHEIMER'S PATIENTS.

...A MICHIGAN AREA AGENCY ON AGING HAS ESTABLISHED AN ELDER CARE SHARE COOPERATIVE PROGRAM IN WHICH RESPITE IN THE HOME IS EXCHANGED FOR EQUILAVENT HOURS OF CARE, WITH NO FINANCIAL COST INVOLVED.

...IN YOUR STATE OF IOWA, MR. CHAIRMAN, THE UNIVERSITY OF KANSAS AND THE AOA REGIONAL OFFICE ARE PROMOTING A COOPERATIVE APPROACH TO INFORMATION DISSEMINATION AND THE DEVELOPMENT OF FAMILY SUPPORT GROUPS IN RURAL AREAS.

...IN NEW YORK CITY, WE HAVE A VERY COST EFFECTIVE PROGRAM WHICH INVOLVES VOLUNTEERS WHO PROVIDE, UNDER PROFESSIONAL SUPERVISION 4 HOURS OF SERVICE EACH WEEK AT THEIR LOCAL CHURCH OR SYNAGOGUE,

THUS ENABLING FAMILY CAREGIVERS SOME "TIME OFF" FOR THEMSELVES .

...AS YOU WELL KNOW, SENATOR METZENBAUM, THE STATE OF OHIO HAS PASSED LEGISLATION THAT WOULD AID VICTIMS OF ALZHEIMER'S DISEASE BY OFFERING TRAINING FOR CAREGIVERS AND BY PROVIDING FOR RESPITE AND HOMEMAKER PILOT PROGRAMS, AMONG ITS MANY FEATURES. IN ADDITION, A NUMBER OF AAAs ARE ADMINISTERING COMMUNITY-BASED LONG TERM CARE SERVICES FOR ALZHEIMER'S PATIENTS AND SOME HAVE MEDICAID WAIVER PROGRAMS FOR IN-HOME CARE, ADULT DAY CARE AND A RANGE OF OTHER SUPPORTIVE SERVICES THAT HELP MAINTAIN ALZHEIMER'S PATIENTS IN THEIR OWN HOMES.

...IN THE STATE OF FLORIDA, A BROAD RANGE OF ALZHEIMER'S DISEASE-RELATED INITIATIVES HAVE BEEN UNDERTAKEN. IN ADDITION TO A STRONG COMMITMENT BY THE STATE, MANY AAAs ARE FUNDING THEIR PROVIDER AGENCIES TO CARRY OUT SERVICES SPECIFICALLY TARGETED TO ALZHEIMER'S PATIENTS AND THEIR FAMILIES. THESE INCLUDE FAMILY SUPPORT GROUPS, A WEEKEND DAY CARE PROGRAM, IN-HOME RESPITE CARE, HOME DELIVERED MEALS AND HOMEMAKER SERVICES, AMONG MANY OTHERS.

WHAT IS CLEAR, HOWEVER, IS THAT DESPITE THE MEASURES UNDERWAY TO MEET THESE EVER-MOUNTING NEEDS, MUCH MORE MUST BE DONE. IT IS OUR HOPE THAT THE BILLS UNDER DISCUSSION TODAY WILL MAKE SOME OF THAT POSSIBLE.

I WANT TO ASSURE YOU OF OUR FULL SUPPORT FOR EXPANDED RESEARCH INTO THE CAUSE, CURE AND PREVENTION OF ALZHEIMER'S DISEASE HIGHLIGHTED IN ALL OF THE BILLS. MOREOVER, I AM PARTICULARLY PLEASED TO NOTE THAT IN A NUMBER OF THE BILLS THERE IS SPECIFIC CONSIDERATION GIVEN TO ENHANCING SERVICES TO FAMILY CAREGIVERS. SENATOR METZENBAUM HAS INTRODUCED TWO VERY FINE BILLS, S.1835 AND S.2183. WE

ARE ESPECIALLY GRATIFIED TO SEE THE INCLUSION OF SUGGESTED AMENDMENTS TO THE OLDER AMERICANS ACT WHICH WOULD DESIGNATE SPECIFIC SERVICES AND NEW AREAS OF RESPONSIBILITY RELATED TO BOTH ALZHEIMER'S VICTIMS AND THEIR FAMILIES. WE STRONGLY ENDORSE THE UTILIZATION OF THE AGING NETWORK'S EXPERTISE AND SERVICE CAPABILITY AS WELL AS THE EXPANDED ROLE OF THE AOA, AND THE STATE UNITS AND AREA AGENCIES ON AGING.

ONE FURTHER NOTE: WE WERE PARTICULARLY PLEASED TO SEE THE RECOMMENDATION IN THE METZENBAUM BILL TO UPDATE THE DISABILITY GUIDELINES OF THE SOCIAL SECURITY ACT TO INCLUDE ALZHEIMER'S DISEASE AS ONE THE DESIGNATED ILLNESSES FOR DISABILITY ALLOWANCE.

IN CONSIDERING SENATOR PRESSLER'S BILL, S.1736, WE FIND THAT THE PROGRAMMATIC CONCEPTS ARE NOTEWORTHY AND IMPORTANT OF PARTICULAR INTEREST IS THE SECTION THAT ENABLES STATES TO COORDINATE THE DEVELOPMENT AND OPERATION OF A WIDE RANGE OF NEEDED SERVICES: DIAGNOSTIC TREATMENT, CARE MANAGEMENT, RESPITE, LEGAL COUNSELING AND EDUCATIONAL SERVICES. OUR EXPERIENCE HAS BEEN THAT THESE ARE MOST NEEDED. WE WOULD HOPE, HOWEVER, THAT THESE ACTIVITIES WOULD NOT BE LIMITED TO THE PUBLIC HEALTH SERVICE BUT THAT THERE WOULD BE A DEFINED LINKAGE BETWEEN THE PUBLIC HEALTH SERVICE AND THE ADMINISTRATION ON AGING.

I HAVE JUST READ A DRAFT COPY OF THE 1986 ALZHEIMER'S DISEASE AND RELATED DEMENTIAS SERVICES RESERACH ACT. I WANT TO COMPLIMENT THE COMMITTEE FOR THEIR EMPHASIS ON "SERVICES RELEVANT RESEARCH". THE SUGGESTED AGENDAS FOR THE NATIONAL INSTITUTE ON AGING, THE NATIONAL INSTITUTE OF MENTAL HEALTH AND THE NATIONAL CENTER FOR HEALTH SERVICES ARE TRULY IMPORTANT AND THE RESULTS OF THE PROPOSED RESEARCH WOULD PROVIDE US WITH A SIGNIFICANT AND TIMELY BODY OF KNOWLEDGE. HOWEVER, IN A VERY QUICK READING, I WAS SURPRISED TO NOTE THE ABSENCE OF ANY ROLE FOR THE ADMINISTRATION ON AGING AND ITS VAST NETWORK OF STATE AND LOCAL UNITS ON AGING. MANY OF THE SERVICES MENTIONED ARE CURRENTLY BEING PROVIDED THROUGH THIS NETWORK AND, I BELIEVE, WE HAVE A VAST DATA BASE

WHICH IS ACCESSIBLE AND AN EXTENSIVE SERVICE NETWORK WHICH COULD BE UTILIZED IN ADDRESSING THE GOALS PROPOSED BY THE 1986 ALZHEIMER'S DISEASE AND RELATED DEMENTIAS SERVICES RESEARCH ACT. MOREOVER, THE INFORMATION IN OUR NEW BOOK, "AGENDAS FOR ACTION", WILL CONFIRM THE ALREADY EXTENSIVE INVOLVEMENT OF THE AGING NETWORK IN ALZHEIMER'S-RELATED PROGRAMS.

IN REVIEWING DISSEMINATION PROCEDURES AND ORGANIZATIONS INVOLVED IN THIS ARENA, I WOULD HOPE THAT THE NATIONWIDE AGING NETWORK WHICH IS IN PLACE WOULD BE A DESIGNATED AND INTEGRAL PART OF THIS EFFORT.

I TRUST THAT YOU WOULD WANT TO BUILD UPON THE SKILLS, EXPERTISE, KNOWLEDGE BASE AND SERVICE SYSTEM NETWORK WITH ITS 56 STATE UNITS ON AGING, 672 AREA AGENCIES ON AGING, 15,000 SERVICE PROVIDERS, AND MILLIONS OF ELDERLY CONSTITUENTS.

I WOULD WECOME THE OPPORTUNITY TO DISCUSS WITH YOUR STAFF OR COMMITTEE MEMBERS THE DETAILS OF THE VARIOUS LEGISLATIVE PROPOSALS AND SOME OF OUR SPECIFIC RECOMMENDATIONS.

ONE FINAL CAVEAT: WE URGE THAT ANY BILL THAT IS PROMULGATED, WILL INCLUDE THE NECESSARY FUNDING AUTHORIZATION IN ORDER TO ENABLE IMPLEMENTATION OF THE RECOMMENDATIONS.

IN CLOSING, SENATOR GRASSLEY, I WANT TO COMMEND YOU FOR HAVING CONVENED THIS IMPORTANT HEARING AND FOR THE INTEREST AND COMMITMENT OF YOU AND YOUR COLLEAGUES IN THE CRITICALLY IMPORTANT ISSUES RELATED TO ALZHEIMER'S DISEASE.

Senator GRASSLEY. Would you impose on me 5 minutes for questioning so I do not go over my time limit, and then I will give Senator Metzenbaum time to ask questions as well.

First of all, Mr. Stone, I think that one or more of the bills before this subcommittee would authorize activities designed to improve diagnostic techniques for Alzheimer's disease and related dementias. And I understand again that the association's national program statement mentions the need for such assessment tools. Would you give me just a short estimation of how high on the priority the development of such a tool would be, considering all the needs in this area?

Mr. STONE. Well, right now, Alzheimer's disease diagnosis is one of exclusion of other dementias. But we do find that education is needed even in the medical community because many patients are diagnosed in nursing homes or even by their own family physicians. Actually, an Alzheimer's diagnosis should come after a thorough workup by a neurologist or a neurological department.

We think we need a lot of education and public awareness in that area, Mr. Chairman.

Senator GRASSLEY. So a very high priority?

Mr. STONE. Yes, because some 30 percent of dementias are reversible.

Senator GRASSLEY. I would ask all three of the panelists to comment on an observation that I hope I have interpreted right from Mr. Stone, in which he noted the association's supports efforts at stimulating the development of alternative delivery systems as well as mechanisms for financing long-term care for Alzheimer's victims.

On this point, I would like to raise the point that it could be objected—I am not saying it has been objected—but it could be objected that from the point of view of designing and paying for long-term care systems, dementia victims should not be singled out for special treatment from other people who also need long-term care services.

I would ask each of you to comment on that, including you, Mr. Stone.

Mr. STONE. As someone who is interested in the human welfare of all citizens, I cannot take exception to the fact that we must treat everybody in this Nation equally.

On the other hand, Mr. Chairman, you know we are the only Western democracy that has no plans for long-term medical care. And I think it is high time that the Nation address itself to this problem. I know that President Reagan addressed to the new Health and Human Services Secretary, Dr. Bowen, the fact that he should come up with a statement on catastrophic illness, and I think that statement is due perhaps the end of this year.

Certainly, Alzheimer's disease is in that realm of catastrophic illness, except that it is the worst of all diseases because it runs such a prolonged course, causing tremendous suffering and hardship for both the victim and the family.

So if we truly are a humane nation, and if we have human considerations for the family, we certainly must address this issue of long-term care.

Senator GRASSLEY. Ms. Gwyther?

Mr. GWYTHER. I think the unpredictable length and course of Alzheimer's disease makes it particularly troublesome. I also think the increasing personal care assistance needs of Alzheimer's patients mean that we need to develop models which could be prototypes for other chronic long-term care illnesses. So that I think what we develop for Alzheimer's disease will turn out to be very helpful for any chronic disabling illness of older people.

Senator GRASSLEY. Commissioner Sainer?

Ms. SAINER. Yes, I would endorse the statement that was just made—both statements. One is that we would want it for the broader population of frail elderly and family caregivers. On the other hand, there are some special distinctive needs for Alzheimer's families, both the length of the illness, as well as the chronic care component, as distinct from acute care component. I think the need for in-home services for a chronic care-disabled population, especially the kind and duration that can pauperize families, is critical.

Senator GRASSLEY. On another point, Commissioner Sainer, how might the existing services of the aging network be effectively meshed with the research activities envisioned by some of these bills that we are considering?

Ms. SAINER. There is a service network out there of close to 700 area agencies and 15,000 service providers that are linked to this service network. What we would like to see is the data and the information of how the services provided through Older American Act funding is supportive of the frail elderly and particularly of early-stage Alzheimer's victims. That is one piece. The second would be whether special demonstration projects, such as the recently funded AOA Alzheimers initiatives, could also be added to the bill of your committee. We have some very fine research organizations that you have highlighted in that bill—but perhaps there might be the service demonstration funds available so that the service network could build on what it already has in place, and direct it and target it to Alzheimer's patients and particularly to Alzheimer's families.

These are a few of the ways in which the linkage might be made. To try to develop a new system or to forget there is a an aging network out there that already addresses the needs of the frail elderly and certainly is increasingly addressing the needs of Alzheimer's families is something that we ought to take into account.

Senator GRASSLEY. Senator Metzenbaum?

Senator METZENBAUM. First of all I would like to commend the panelists, and I would like to particularly commend Jerry Stone for his work with ADRDA. The chapters in Ohio with whom I have worked I know are very grateful that they have someone to turn to for help and support. And I think it is rather interesting today that we are talking about various bills, and this one has that good point, and that one has another good point.

What wonderful progress we have made to the point where members of the U.S. Senate and the House of Representatives are competing with ideas as to what to do about this dreaded illness. We have come a long way in that respect, and that to me is healthy competition, and I am not at all concerned that it will in any way turn into a negative.

Mr. Stone, how would you characterize the change in public awareness since ADRDA—how do you pronounce it—well, it does not matter——

Mr. STONE. ADRDA. It is a toughie, but we are stuck with it.

Well, I think you said it very well, Senator, in your opening remarks. There is far greater public awareness. Many more are now cognizant of this disease, particularly the older population. I keep recalling the time I first appeared before this committee asked whether we could get $100,000 for a program on public awareness. Today, I note, Senator, that your home State of Ohio is spending $1,850,000 for research and education. So I think the figures speak for themselves.

A recent survey conducted by the University of California reveals that, some 80 percent of the population now know that Alzheimer's is a disease. We could not say that 6 years ago.

So we have come a long way, in at least exhibiting the fact, as someone said, that there is no such thing as senility.

Senator METZENBAUM. Do you have any suggestions as to what the Federal Government could do over and above that which they are doing with respect to the matter of awareness?

Mr. STONE. No, I have no suggestions, except each one of these bills that come through really is just like throwing a pebble into the water. Ripples come out of that into each community. So that the awareness is enhanced, really, by the Federal Government's action, and I think that is what we need right now. We have the awareness. Now we need more action.

Senator METZENBAUM. Ten years ago, the National Institutes of Health was spending less than $5 million on research into Alzheimer's disease. That amount has since grown to about $53 million. And I am proud to say that I think I played some role in that being brought about.

My question is what have we bought with this increase in terms of knowledge about the cause and treatment of the disease—and if any one of you would care to answer, please feel free to do so.

Mr. STONE. I will defer to the other panelists, and I will conclude, if you wish, Senator.

Ms. GWYTHER. I think the NIA research centers have drawn attention to the biomedical research needs of Alzheimer's patients. And I think what we have done is we have learned a lot more about the potential causes and what happens in the process of Alzheimer's disease. What we need to do is learn more about what may be causing it more definitively and what can be done to treat it or potentially prevent it.

Senator METZENBAUM. How would you go about doing that?

Ms. GWYTHER. I am not a biomedical researcher, so I do not feel qualified to answer that.

Senator METZENBAUM. Commissioner, do you have any ideas on how to target the available funds to go and get the most bang for the buck?

Ms. SAINER. Yes. I think that there is no question that home care and respite care is the most undermet need that there is. For the population that is Medicaid-eligible in various States and communities, there are some services available.

Unfortunately, for those who are not able to meet those super-low income eligibility requirements, we have a large population who are carrying financial burdens as well as caregiving burdens, which are very, very difficult. I know that in our city, for instance, 18 percent of our 1 million people are Medicaid-eligible. There are an additional 52 percent of those 1 million, who have incomes between $5,000 and $10,000; thus, almost 70 percent of our New York City older population have incomes under $10,000.

When you take that 52 percent who are not eligible for any public entitlements at the present time, and recognize that Medicare does not cover any of the costs of in-home service for this population, then this is the issue that really has to be addressed. If we are not to bring more people into poverty, let more people become burdens to the public system, or force more people into nursing homes, then is is necessary to have more in-home support services available.

So if you are asking me for one issue which is critical, I think that would be the one.

Senator METZENBAUM. Mr. Stone, if we had a limited amount of money, and we wanted to place that money in the most useful arena or area, how would you suggest we spend it? And I am going to ask you, Ms. Gwyther, and you, commissioner, the same question.

Mr. STONE. If you are talking about research, I think as Commissioner Sainer indicated, you have got two problems. One, of course, is the continuing problem of basic research, and that is to find the cause and cure for Alzheimer's disease. The fact that we are spending $53 million is heartening, but basically, you are spending about $20 per victim when you get right down to it.

And, although I do not like to measure it against research on other diseases, I think that we are on the very low end of the totem pole.

Basic research really is comprised of bits and pieces that make up a jigsaw puzzle. Eventually, scientists from different vantage points, whether they are in the 10 Alzheimer's centers or in other research institutions—they write their papers, they do their basic research, and there is a kind of piggybacking arrangement where you learn from each other.

It is not like the old days, perhaps, when Archimedes went into the bathtub and said, "Eureka, I have found it." I think that research in as complex and complicated a disease as Alzheimer's must be on those terms. But it takes money, time and energy.

So I would say that part of that money, or perhaps a greater portion of that money, should be spent on basic research.

Applied research is what Ms. Gwyther and Commissioner Sainer were talking about. We have got to find better ways of treatment, of handling the victims, as well as assisting with the family problems, emotional, legal, social, all the consequences that a family has with an AD victim. And so far it has been trial and error, but I think the proposal that there be one basic clearinghouse for information goes a long way toward solving that problem. I believe that that would be progress.

I could not begin to tell you what the amount should be, but I can tell you it should be a lot more than what we are presently spending.

Senator METZENBAUM. Ms. Gwyther?

Ms. GWYTHER. I think families on the front line want something active done now that may be of help to their relatives. At a minimum it will reduce or combat the negative feeling that nothing can be done for Alzheimer's patients.

I think we have limited evidence that enriched programs, enriched or specially-designed environments, caregiver programs, can have some positive impact. And I think if we do not invest in those programs and in the rigorous evaluation of those programs, then the long-term costs for the secondary or third victims of Alzheimer's disease are going to be even greater.

Senator METZENBAUM. Thank you.

Commissioner Sainer?

Ms. SAINER. I want to strongly support—even though, obviously, I am speaking for the service world—more research efforts and the need for expanded research, which ran through all the bills that were presented today. That is basic.

But you mentioned in your bill, Senator, tax credits which might be given, incentives which would enable families to sustain their family members in their homes.

I was particularly interested in the comprehensive nature of your earlier bill, and recognize that the later bill was a little more limited. But I think it is also important, in a cost-effective fashion, to build on what already exists and not to set up completely new systems. Thus, if one adds to the service capacity of those who are providing services, this would be very important. The nature of those services, we would certainly be glad to discuss further with you.

Senator METZENBAUM. Thank you. I might say that the difference in my first bill and the second bill is that the first bill is really the better bill, but that bill, I cannot get a hearing on. The second bill, I can get a hearing on because I am on the committee.

Ms. SAINER. Well, we endorse that second one and are ready to move with it, too.

Senator METZENBAUM. I think that is the difference in the modus operandi.

Mr. STONE. May I add just a word, Senator? We are trying creative approaches. I am going to be here next month with the AOA, and with a large private foundation, in the hopes of trying to work out a tripartite arrangement with ADRDA, the private foundation, and the Government to fund some demonstration respite care centers. This could be the first time that that kind of a tripartite arrangement has been tried. I am hoping it will be successful. And it is in line with the fact that we are just not asking Government to do all this, that the private sector is going to be involved. And I think that should be heartening.

Senator METZENBAUM. Thank you very much, and in behalf of the Chairman, myself and all others who are interested, thanks for your participation and continued concern.

Our next panel consists of Dr. Robert Cook-Deegan, senior analyst and project director of the OTA; Dr. Peter Whitehouse, Divi-

sion of Behavioral Neurology, Case Western Reserve University; and Dr. Kathleen Buckwalter, University of Iowa, Iowa City, IA.

Dr. Cook-Deegan, we are happy to have you with us. I think you heard the rules of the Chairman with regard to the 5-minute rule; you get 1 minute after that, and then the guillotine comes down.

Please proceed.

STATEMENTS OF DR. ROBERT COOK-DEEGAN, SENIOR ANALYST AND PROJECT DIRECTOR, OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS; DR. PETER J. WHITEHOUSE, DIRECTOR, DIVISION OF BEHAVIORAL NEUROLOGY, CASE WESTERN RESERVE UNIVERSITY; AND DR. KATHLEEN C. BUCKWALTER, ASSOCIATE PROFESSOR, COLLEGE OF NURSING, UNIVERSITY OF IOWA, IOWA CITY, IA

Dr. COOK-DEEGAN. Being an employee of the U.S. Congress, I cannot dispense with expressing my gratitude to the Chairman and you, Senator Metzenbaum, for letting me appear here.

My name is Dr. Robert Cook-Deegan, and I am a physician acting as project director at the Congressional Office of Technology Assessment, directing a project on dementia and related issues since November 1984.

This subcommittee has expressed considerable interest in the project and has contributed greatly to its preparation. The subcommittee, along with the Subcommittee on Human Services of the House Select Committee on Aging, requested, for example, that OTA hold two workshops of national experts. This was also cosponsored by ADRDA. Workshops were held in February and May. The first was on health services research, and the second was on financing long-term care for patients with dementia.

A lot of what I am going to say today is based on what we have been doing since 1984 on the OTA project, and the results of those two workshops.

I will focus on Federal policy issues, because you are going to hear the view from the trenches from the next two witnesses.

Specifically, Federal problems posed by dementing illness can be roughly grouped into two categories: research and provision of services. Research can be further divided into basic biological research, clinical research, and research on services delivery, the latter often called health services research. Basic biological research is central to understanding that cause of various disorders causing dementia and includes genetics, neuroscience, biochemistry and pathology, and is directed at benefiting future patients through discoveries that suggest new drugs, diagnostic methods, or means of prevention.

Clinical research builds on basic knowledge and emphasizes application to medical practice. Health services research in contrast, focuses on the needs of current victims, costs of care, quality and access to current services in medical and social service practice.

Health services research works by evaluating current practices and developing innovative techniques. It aims to improve the care of those who now have the dementia or will develop it in the future.

Basic and clinical research are thus central to reducing the future magnitude of the public health consequences, while health services research can both reduce the problem in the future and improve the care of those who have the disease now. It is also a backup strategy in case biomedical and clinical research do not come up with an alternate solution.

In contrast to those three kinds of research, provision of services includes both acute medical care and long-term care in numerous settings—in homes, nursing homes, board and care facilities, adult daycare centers, hospitals, mental health centers, senior centers and clinics, and I am sure some others that I have not thought of. It also includes coordination of the various services available to a person needing them.

While patients with dementia need acute medical care, the bulk of service needs caused by diminished mental capacity fall into what is called the long-term care system. That system is currently a patchwork of diverse services that are not well-coordinated, many of which are unavailable in most regions. This contrasts strongly with the ideal of a continuum of services from initial diagnosis to death.

Long-term care is a system, but a complex one, that often does not work very well, particularly for those with severe disabilities, including those with dementia.

Difficulties in long-term care can be traced to lack of funding for the services most needed, including personal care, caregiver respite, and assistance with chores, to fragmentation of services among different administrative umbrellas—that is, aging services, mental health services, medical services, and long-term care services—and I would add social services—and also to lack of information about what services are needed for which problems, and which ones work, or how much they cost.

Those with dementia constitute a large fraction of those needing long-term care and social support. Those with dementia account for 40 to 70 percent of those in nursing homes, for example, yet there is remarkably little known about what services they need, which ones they use, how much they spend for them, and how different services can complement one another to meet the needs of those with dementia. This was a strong point of consensus at both of the two recent workshops.

Construction of prudent public policies, including Federal policies, will thus require substantially more information about quality, access, and costs of services.

Each of the bills before the committee would encourage the gathering, analysis and dissemination of information about patients with dementia.

A few goals of the legislation can be discerned. Each bill recognizes the need for a balanced attack on the problems arising from dementia. Some bills emphasize diagnosis and treatment, while others focus on biomedical research. Still others have a service delivery component.

I will focus the last minute of my talk here on health services research, because I think it is the one area that needs the most support.

In contrast to the $50 million being spent for basic biomedical research in this country—incidentally, that $50 million is a revised figure based on new numbers; the $56 and $54 million figures that I had before are incorrect, those are too high—in health services research in contrast, we have only been able to find $1.3 to $2 million being spent on health services research focused on those with dementia. That compares to $50 million in basic research, about $4.4 billion being spent for long-term care alone of those with dementia from the Federal Government, and the $40 billion spent overall in the care of dementia in the United States.

With that, I will leave it to the other panelists to provide more details.

Thank you.

[The prepared statement of Dr. Cook-Deegan and responses to questions submitted by Senators Grassley and Metzenbaum follow:]

TESTIMONY OF ROBERT M. COOK-DEEGAN, M.D.
SENIOR ANALYST AND PROJECT DIRECTOR
OFFICE OF TECHNOLOGY ASSESSMENT, U. S. CONGRESS
BEFORE THE SUBCOMMITTEE ON AGING
COMMITTEE ON LABOR AND HUMAN RESOURCES
U. S. SENATE

FEDERAL SUPPORT FOR RESEARCH ON DEMENTIA

July 22, 1986

Mr. Chairman,

Thank you for the opportunity to testify before your subcommittee. My name is Dr. Robert Cook-Deegan. I am a physician working as a senior analyst at the congressional Office of Technology Assessment (OTA), and have been responsible for directing a study of dementia and related issues since November, 1984. Your subcommittee has expressed considerable interest in the project and has contributed greatly to its preparation. Your subcommittee (along with the Subcommittee on Human Services of the House Select Committee on Aging) requested, for example that OTA hold two workshops of national experts. These workshops were cosponsored by both requesting committees and the Alzheimer's Disease and Related Disorders Association (ADRDA). (The names of the OTA advisory panel and the participants at each of the workshops are included with my written statement.) The first workshop, on health services research, was held in February; the second, on financing care for patients with dementia, was held in May. Those workshops and other information gathered for the OTA report provide the background for my statement today.

Testimony of Robert M. Cook-Deegan, M.D., Office of Technology Assessment 2

Federal issues related to dementia have become much more prominent in recent years, due to the staggering number of people affected (1.5 million Americans are estimated to have severe dementia today), the intense strains imposed on families in caring for them, the costs of providing care, and rising awareness of dementia in health professions and the general public. This interest is reflected in the number of bills specifically noting Alzheimer's disease in recent Congresses. The number of such bills has risen from none in the 96th Congress, to 3 in the 97th Congress, to 27 in the 98th Congress; there are currently 32 bills pending in the 99th Congress, with several others being prepared. Many of these are under consideration today. I am not in a position, as an OTA analyst, to make recommendations about any one bill. I can, however, comment on some of the conceptual foundations that underlie the current bills and highlight some of the Federal functions that might be productively addressed in new legislation. A more detailed discussion of Federal responsibilities, and options for meeting them, will be available when our report is released later this year.

Federal problems posed by dementing illness can be roughly grouped into two categories: research and provision of services. Research can be further divided into basic biological research, clinical research, and research on service delivery -- often called health services research. Basic biological research is central to understanding the cause of the various disorders causing dementia. It includes genetics, neuroscience, biochemistry, and pathology, and is directed at benefitting future patients through discoveries that suggest new drugs, diagnostic methods, or preventive measures. Clinical research builds on basic knowledge and emphasizes application to medical practice. Health services research focuses on needs, costs, quality, and access by evaluating current practice and designing innovative methods. It aims to improve the care of those who now have dementia or will develop it in the future. Basic and clinical research are thus central to reducing the future magnitude of the public health consequences of dementia, while health services research can improve the lot of those whose disability

cannot be prevented or reversed. Health services research is thus essential not only to current patients, but as a "backup" strategy to minimize the social consequences of dementia if scientists do not discover an effective treatment or means of prevention soon.

Provision of services includes both acute medical care and long-term care in numerous settings: homes, nursing homes, board and care facilities, adult day care centers, hospitals, mental health centers, senior centers, and clinics. It also includes coordination of the various services available to a person needing them.

While patients with dementia need acute medical care, the bulk of service needs (caused by diminished mental capacities) fall into what is called the long-term care system. The long-term care system is currently a patchwork of diverse services that are not well coordinated, many of which are unavailable in most regions. This contrasts strongly with the ideal of a continuum of services from initial diagnosis to death. Long-term care is a system, but a complex one that often does not work very well, particularly for those with severe disabilities that last for years -- including the vast majority of those with dementia. Difficultites can be traced to lack of funding for the services most needed (personal care, caregiver respite, and assistance with chores), fragmentation of services among different administrative umbrellas (aging, mental health, medical, and long-term care), and lack of information about what services are needed for which problems.

Those with dementia constitute a large fraction of those needing long-term care and social support. They account for 40 to 70 percent of those in nursing homes, for example, yet there is remarkably little known about what services they need, which ones they use, how much they spend for them, and how different services can complement one another to meet the needs of people with dementia. This was a strong point of consensus at each of the recent workshops. Construction of prudent public policies will thus require substantially more information about quality, access, and costs of services.

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Each of the bills before the committee would encourage the gathering, analysis, and dissemination of information about patients with dementia. A few goals of such legislation can be discerned: each recognizes the need for a balanced attack on the problems arising from dementia. Some bills emphasize diagnosis and treatment, some focus on biomedical research, and others concentrate on service delivery. A few generalizations can be made about current policies. First, support for basic research has risen dramatically, from approximately $4 million in 1976 to $56 million in 1985. This increase is undoubtedly related to progress in research, reflected in an increase of medical publications on "Alzheimer's disease" and "dementia" amd "senility" from 30 in 1972 to 87 in 1976 to 548 in 1985. These publications are primarily about basic and clinical research. The Federal Government has taken a clear lead in supporting biomedical research on dementia, with supplementation from nongovernmental organizations such as the ADRDA, the Howard Hughes Medical Institute, the John Douglas French Foundation, and the American Federation for Aging Research. Continued support would likely sustain the growth of knowledge, and biomedical research is the only hope for eventually conquering the problem of dementia. Several of the bills before the committee would intensify the scientific investigation of disorders causing dementia.

In health services research, the history of support is not as strong. The dearth of quantitative data on services used, services needed, and costs specific to dementia patients is striking. Several fundamental questions cannot be answered at present, as evidenced by the list of questions discussed at the February workshop. (A list of similar questions is included in the written supplement to this testimony.) There are some articles on medical services (although many fewer than about drug treatment or the cause of Alzheimer's disease), a few about nursing home care, and only a handful about respite care, home care, and day care. Yet respite care, day care, and home care are the services most sought by those caring for people with dementia, as revealed in a poll

commissioned by OTA (and performed by Yankelovich, Skelly and White). The highest priorities in that poll were: more information about services, wider availability of home services, and relief of caregiver burden (respite care). Pilot projects are springing up across the nation to deal with these needs. Most of the projects are supported by State governments, ADRDA chapters and other family support groups, nursing home organizations, and medical corporations. In general, states and nongovernment organizations are far ahead of the Federal Government in creating innovative services for dementia patients.* Yet there is no reliable coordination of such experiments, and little opportunity for comparative analysis and evaluation. A federal role in gathering data, analyzing them, and disseminating results might reduce the amount of "wheel spinning" and unproductive duplication of effort by groups working in different locations

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* The National Institute on Aging (NIA), the Administration on Aging (AoA), the National Institute of Mental Health (NIMH) and the Health Care Financing Administration (HCFA) each support a few projects on dementia, most of which are small parts of larger projects on long-term care. In 1984, the Federal Government spent $200 million on health services research overall, or 1/20 of 1 percent of its total budget for health care ($387 billion), and 3.2 percent of the budget for biomedical research ($6.154 billion).

A survey of Federal health services research specifically focused on dementia patients conducted in April, 1986, by the Congressional Research Service, found that three agencies — AoA, NIMH, and HCFA have recently issued grant solicitations requesting projects to address the needs of adults with dementia. At that time, AoA was funding 12 projects, with the following spending history: FY84: $163,817 for 2 projects; FY85 $1,127,618 for 12 projects; FY86 $431,400 in continuing and $500,000 estimated new funding for projects. NIA estimated that it would fund $426,000 for research on care of dementia patients in FY86. NIMH funded 3 projects either fully or partially focused on assistance to dementia patients and their families in 1983, 4 in 1984, 7 in 1985, and 7 in 1986 (budgets not available). HCFA had not previously funded projects specifically on dementia, but planned to add an assessment of mental function to demonstration projects in at least one state in 1986. The National Center for Health Services Research and Office of Health Technology Assessment (NCHSR/OHTA) had not funded specific projects on dementia and had not issued solicitations for them.

Estimated total Federal spending on health services research related to dementia is thus in the range of $1.3 to 2 million, corresponding roughly to 3 percent of biomedical research ($54 million), and 1/200 of 1 percent of estimated national costs of dementing illness ($24 to 48 billion).

without overall coordination. This role is likely to be relatively inexpensive compared to either basic biomedical research or, especially, direct provision or funding of services.

Opinions differ radically about the role of the Federal Government in providing services, particularly long-term care. Currently, Medicare covers less than 2 percent of long-term care costs, and those covered are not really long-term care so much as short-term medical care following hospital discharge. Dementia patients, in contrast, need primarily nonmedical services for protracted periods, and these needs are not covered by Medicare at all. Medicaid is a health program jointly funded by the State and Federal Governments, and administered by the States. It pays for 43 percent of the national costs of nursing home care, and covers at least 70 percent of nursing home residents nationwide. It does cover some of the services used by those with dementia, and dementia patients are believed to rely heavily on this public subsidy program to finance their care. Even here, however, the extent to which those with dementia use Medicaid is not known, and long-term care other than nursing home care is only sparsely covered in a few geographic regions. Legislation touching on Medicaid policies would have a dramatic impact on those with dementia, but given the amount and quality of current information, the type of impact is unpredictable. The bills under discussion do not primarily address Medicaid policies (although several of the bills would affect some services available under Medicaid), and extended discussion of the options for doing so is thus not appropriate. I mention the importance of Medicaid because wise policy decisions made about changes in it may well depend on information generated as a consequence of successful implementation of one of the bills currently before the committee.

I thank you for the opportunity to testify before you today, and welcome the opportunity to respond to any questions that you or other members of the subcommittee may have.

Testimony of Robert M. Cook-Deegan, M.D., Office of Technology Assessment 7

WRITTEN SUPPLEMENT TO TESTIMONY

QUESTIONS ABOUT SERVICE NEEDS OF DEMENTIA PATIENTS

This is a list of questions that are relevant to public policy affecting the care of patients with dementia. A similar set of questions was used to guide discussion at a workshop of experts in February. Those who participated in that workshop are also listed below. Major questions are underlined, with relevant information and related questions following.

EPIDEMIOLOGY

How many people have dementia? Current estimates are 1.5 to 5 million Americans suffering from dementing conditions (or Alzheimer's Disease, depending on the source). This expresses a certainty that is belied by the epidemiological literature. Many epidemiological surveys have been started, but do they agree, and can they be compared to one another? If so, what do they say? If not, what can be done to get more accurate projections? What does current epidemiology tell us about subtypes, etc, and what relevance do current results have to health and long-term care policy? In particular, what do we know about the incidence and prevalence of dementia among the very old? How important are genetic factors? What is the reliability of future projections? What can be done to reduce uncertainty?

Do 40 to 70 percent of patients in nursing homes have dementia? What are current estimates based on, and how reliable are they? What can be said about the prevalence of dementia in institutions and in the community?

Are there one to three times as many patients with mild dementia as severe?

Are there subtypes of many of the dementias, including Alzheimer's disease?

What is the course of illness for most of the dementias, and how does it relate to service needs?

Can existing epidemiological studies that use different assessment questionnaires be compared?

ASSESSMENT

Is it possible to distinguish patients with dementia from those with other problems? If so, how reliable, valid, and auditable are the measures? If not, how can better measures be developed?

Are there data on diagnosis, severity of illness, degree and type of functional impairment, and availability of informal supports? These are necessary for planning services.

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SERVICE NEEDS

Is it true that those with mild dementia do not need as many services as those with severe symptoms? Does severity relate to current service use patterns? What are the care needs of those with mild dementia? Are there ways to buttress the informal care network?

Are patients with dementia residing in nursing homes because the disease causing their dementia renders them incapable of personal care? It is presumed that all patients in institutions who have dementia are institutionalized due to the dementia. Yet many patients with dementia might have other disabilities that either contribute to or more directly cause their institutional placement? Do we know?

Is the burden of caring for patients with dementia more severe than for other disorders? There is ample evidence of caregiver stress, but arguments for special services restricted to dementia patients would also presume that the situation is worse for dementia than for other conditions. Is there such comparative evidence? Is stress different in different settings? For families? For professionals?

Are 'long-term care' needs of patients with dementia primarily personal care and caregiver support rather than medical treatment?

AVAILABILITY OF AND ACCESS TO SERVICES

Do public programs cover fewer services needed by patients with dementia and their families than for other disorders?

Are patients with dementia excluded from some service programs because their needs are not "medical?"

Are patients with dementia excluded from some facilities because demented patients are difficult and expensive to care for (or at least perceived as such)?

Does special care for patients with dementia reduce disability? Current long-term care methods encourage excess disability and learned dependence. Special care units and programs for patients with Alzheimer's disease or for demented patients are rapidly proliferating. What can be said about their success? What can be said about their replicability? Which kinds of patients can benefit from special care? What are the essential components of special care programs? How can we encourage innovative programs? If such programs become widespread, what will the standards for care be? How can quality be assured, if reimbursed separately, at what rate and contingent on what staffing, program, or architectural factors? For what stages of the illness are special care units useful?

Is most long-term care now given through 'informal' services by family or volunteers (current estimates range from 70 to 90 percent)? Is the fraction the same for patients with dementia as for other disorders? What does the 'percent' services mean? What services can appropriately be provided by family, friends, and volunteers? Which cannot?

Would many families and patients, not currently receiving long-term care services under Medicaid and Medicare, use them if they became more widely available or less costly?

Would availability of home care, respite care, day care, and other services prevent or delay nursing home admission, thus saving government funds? Current analysis suggests that community-based services may not prevent nursing home placement, but rather supplement it. This portends increased costs for new programs (e.g., home care, day care, and personal services) with little direct substitution for current nursing home

use. Is this true in states that have ample nursing home beds? Is it true in states that have supported experimental approaches to community-based and personal care services?

What is the availability of services in different geographic regions? In rural areas? Among the indigent? Among minority groups?

Are those with dementia with onset in middle age being granted eligibility for disability programs? Does this differ among the States?

COST OF CARE

What is the cost of dementia? To the nation? To the Federal Government? To state and local governments? Cost estimates of $24 to 48 billion have been ascribed to care of patients with dementia in the United States each year (a figure of $30 or 36 billion for Alzheimer's disease alone). How reliable are such cost projections? What costs are being included? Excluded? What can justifiably be said about costs?

Do families transfer assets -- to 'artificially' impoverish the person with dementia or themselves -- in order to qualify for Medicaid services? The longevity of the illnesses, the duration from diagnosis to need for services (often longer than the 2 year limit on transfer of assets), the high cost of care, and protracted need for nursing home care for many patients make this especially relevant for patients with dementia and their families.

Would improving the care of residents with dementia cost more than current methods? This is widely believed, although a few pilot programs do not cost more than the national cost of nursing home beds; other programs are significantly more expensive. Resolving this question will bear on incentives to provide specialized care for dementia residents.

Are those with dementia difficult, and therefore expensive, to care for?

Are those with dementia more likely to receive Medicaid benefits than other types of patients? It is argued that patients with dementia tend to enter facilities either for long periods or permanently. This may make them more likely to "spend down" while in a nursing home, and become eligible for Medicaid. Are there data on Medicaid coverage rates for patients with dementia compared to other groups? If so, are there any data on relative costs?

QUALITY ASSURANCE

Must quality assurance methods in settings other than nursing homes (e.g. adult day care, respite care, home-health care) be structured differently? The size and nature of these facilities may make a formal regulatory system impractical or undesirable in that such regulations may create disincentives to individuals seeking to establish these programs. How can alternatives to nursing homes be encouraged while ensuring that quality care will be provided?

Are outcome-oriented measures more effective mechanisms through which to ensure the delivery of quality care than facility-oriented inspection and procedural requirements. What are these outcome measures? Incontinence? Wandering? Frequency of catastrophic emotional reactions? Sleeplessness? Falls? Use of medication? Type or intensity of behavioral symptoms? Reported satisfaction of patients or family surrogates? How could client-centered data be cheaply, accurately, and effectively gathered and analyzed to assure quality care?

Are there quantifiable patient-outcome characteristics that are reliable, valid, and auditable measures of quality care? If so, can those that pertain to dementia patients be identified? Patients with dementia cannot clearly articulate their needs nor protect

themselves from poor care. Does this put them at special risk of abuse or neglect? Is there any evidence of this?

Is quality of care more difficult to assure in board and care facilities and home care than in nursing homes?

PARTICIPANTS IN THE OTA WORKSHOP ON HEALTH SERVICES RESEARCH ON LONG-TERM CARE OF PATIENTS WITH DEMENTIA

February 24, 1986

**Workshop co-sponsored by the Subcommittee on Aging
Senate Committee on Labor and Human Resources,
Subcommittee on Human Services
House Select Committee on Aging, and
Alzheimer's Disease and Related Disorders Association**

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PARTICIPANTS IN THE OTA WORKSHOP ON
FINANCING LONG-TERM CARE FOR PATIENTS WITH DEMENTIA
19 May 1986
Workshop co-sponsored by the Subcommittee on Aging, Senate Committee on Labor and Human Resources, Subcommittee on Human Services, House Select Committee on Aging, and Alzheimer's Disease and Related Disorders Association

T. Franklin Williams, M.D., chairman
Director, National Institute on Aging

Discussion paper by *Karen Davis, Ph.D., and Patricia Neuman*
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(1)

BOB COOK-DEEGAN

ONE OF THE THINGS THAT CAME OUT IN THE WORKSHOP ON SERVICES-RELEVANT RESEARCH ON ALZHEIMER'S DISEASE WAS THAT THERE IS A CONSIDERABLE AMOUNT OF INNOVATIVE ACTIVITY GOING ON AROUND THE COUNTRY DESIGNED TO IMPROVE THE CARE OF ALZHEIMER'S VICTIMS AND PROVIDE SUPPORT AND ASSISTANCE TO THEIR FAMILIES.

IN YOUR CAPACITY AS DIRECTOR OF THE O.T.A. PROJECT ON DEMENTIA YOU HAVE HAD A CHANCE TO SEE A LOT OF THIS ACTIVITY. CAN YOU GIVE US AN IDEA OF THE VARIETY OF ACTIVITY WHICH IS UNDERWAY, OF WHAT WE KNOW ABOUT IT, AND WHETHER WE KNOW MUCH ABOUT IT OR NOT MAKES ANY DIFFERENCE?

(2)

BOB COOK-DEEGAN

YOU MENTIONED THE REPORT OF YOUR PROJECT ON ALZHEIMER'S DISEASE. WHEN DO YOU EXPECT THIS TO BE FINISHED AND WILL IT CONTAIN ANY RECOMMENDATIONS WITH RESPECT TO SERVICES-RELEVANT RESEARCH ON ALZHEIMER'S DISEASE?

(3)

BOB COOK-DEEGAN

YOU NOTED THAT A CONCLUSION OF THE WORKSHOP ON SERVICES-RELEVANT RESEARCH ON ALZHEIMER'S DISEASE WAS THAT CONSTRUCTION OF PRUDENT PUBLIC POLICIES WILL REQUIRE SUBSTANTIALLY MORE INFORMATION ABOUT QUALITY, ACCESS AND COSTS OF SERVICES FOR THIS POPULATION.

LET ME PLAY DEVIL'S ADVOCATE FOR A MOMENT. OVER THE LAST DECADE THERE HAS BEEN A GREAT DEAL WRITTEN ON LONG TERM CARE SERVICES AND SYSTEMS, WHICH IS WHAT WE ARE TALKING ABOUT HERE FOR THIS POPULATION. WHY DO WE NEED MORE RESEARCH ON THIS TOPIC?

QUESTIONS FOR PANEL THREE (DR. ROBERT COOK-DEEGAN, OFFICE OF TECHNOLOGY ASSESSMENT; DR. PETER WHITEHOUSE, JOHNS HOPKINS; DR. KITTY BUCKWALTER, UNIVERSITY OF IOWA)

BOB COOK-DEEGAN

(4) DO YOU KNOW HOW MUCH IS PRESENTLY BEING SPENT BY THE FEDERAL GOVERNMENT ON SERVICES RELEVANT RESEARCH ON ALZHEIMER'S DISEASE?

QUESTIONS FOR DR. ROBERT COOK-DEEGAN FROM SENATOR METZENBAUM REGARDING ALZHEIMER'S DISEASE

PRIORITIES

(5) GIVEN OUR CURRENT BUDGET RESTRICTIONS, HOW WOULD YOU ALLOCATE FUNDS FOR ALZHEIMER'S DISEASE? WHAT PROPORTION FOR BASIC BIOMEDICAL RESEARCH? FOR HEALTH SERVICES RESEARCH? FOR EDUCATIONAL EFFORTS? FOR FAMILY SUPPORT SERVICES? WHAT FACTORS DO WE NEED TO CONSIDER IN MAKING SUCH DECISIONS?

FINANCIAL SUPPORT

(6) WERE THERE RECOMMENDATIONS CONCERNING FINANCIAL SUPPORT FOR THE LONG TERM CARE REQUIRED BY ALZHEIMER'S VICTIMS? SHOULD WE BE GETTING INPUT FROM FAMILIES, AS WELL AS PRIVATE INSURERS, VOLUNTARY ORGANIZATIONS, AS WELL AS FEDERAL AND STATE AGENCIES?

COORDINATION

(7) WAS THERE ANY CONSENSUS AT THE WORKSHOPS AS TO LEADERSHIP OF A COORDINATED EFFORT? WHO NEEDS TO BE INVOLVED? THE NATIONAL AGENDA OR ADRDA INCLUDES A RECOMMENDATION FOR A NATIONAL COUNCIL ON ALZHEIMER'S DISEASE. WOULD YOU COMMENT ON THE POTENTIAL OF A NATIONAL COUNCIL TO LEAD THE EFFORT.

VETERANS ADMINISTRATION

(8) IS THE VA IN A POSITION TO DO LONGITUDINAL STUDIES OF ALZHEIMER'S VICTIMS?

CAN THE VA, AT THE VERY LEAST, PLAY A ROLE IN DIAGNOSIS, ASSESSMENT, MONITORING AND FOLLOW-UP?

CAN THE VA PROVIDE TECHNICAL ASSISTANCE TO OTHER PROGRAMS AND AGENCIES?

TRAINING

(9) HOW DO WE DEVELOP THE NEEDED TRAINING MATERIALS AND TRAINING STANDARDS, AND HOW DO WE DELIVER THE TRAINING NEEDED TO ALL THE GROUPS INVOLVED?

Reply to questions: Robert Cook-Deegan 1

Answers to written questions from July 22 hearing
on health services research for those with dementia

1. There are many experiments on special care for those with dementia across the country. We estimate that 150 to 200 such programs exist in nursing homes, day care centers, home care service agencies, and ADRDA chapters. The centers have tended to crop up independently of one another (with a few exceptions such as the Hillhaven corporation special units at nursing homes). None of the units or programs has been specifically funded by the Federal Government, although some Federal funds have been channelled to pay for care through block grants and Medicaid cost sharing with State and local governments.

I believe it is too early to give the final verdict on efficacy of the special units. There is a tremendous range in quality and efficacy of the special programs. Some are mere marketing ploys to attract private pay patients to facilities that serve as warehouses. Most units, however, are legitimate attempts to improve the care of those with dementia. Some units – such as those in Pennsylvania, at the University of Michigan, the Hillhaven units, and Hebrew Homes – are setting a new, higher standard of care. I think that it is also premature to set guidelines for delivery of care or criteria for which patients do best in special units. It is my own judgment that these special dementia care units will require evaluation over the next several years, and we are now in the early stages of fermentation, with many innovative ideas yet to be discovered. Special attention to the problems of those with dementia will improve care, and in doing so will improve the lot of the majority of those using long-term care. I believe the new burst of interest is long overdue and welcome.

2. The OTA report on dementia will not contain any recommendations about health services research. This is because OTA reports by statute cannot make recommendations, but rather provide background, analysis, and a list of options. Some of the most important options in our report will bear on health services research. Health services research is among the areas that could be quickly and inexpensively addressed by the Federal Government. Filling the gap in knowledge about health service use and delivery would not only help the Federal Government in wisely using its health care dollars, but would also assist states and private companies in discerning opportunities for improvement.

3. I agree that a great deal has been written about long-term care in the last several decades. I would only observe that much of what has been written is based on very few sources of original data. There is, in my opinion, very little really known about long-term care. Much of what has been written is an explanation of how badly the system works.

At the February workshop on health services research, we had some of the most knowledgeable people in the country sitting around one table. There was consensus among them that we do not know the answers to such questions as: How many patients with dementia are there? How many are in nursing homes? Of those in nursing homes, how many are there because they have dementia (as opposed to some other cause)? How can we predict which people will need nursing home care? Which patients can best use day care or home care? Are there measures of quality care for those with dementia?

When I say we do not know the answers, this does not mean that there is general agreement but no quantitative estimate to the last decimal place. I mean we do not have any idea at all. We cannot even piece various studies together to give a coherent set of hypotheses to test.

If you will permit me the luxury of an analogy, our state of knowledge about long-term care now is at about the level of knowledge of genetics before Mendel and Morgan, or acute medical care before the age of antibiotics. It is not even clear exactly which questions are most important to ask. Analysis has centered on aggregate data that cannot reliably differentiate patients with dementia from those with transient confusion, mental retardation, or psychiatric illness. Yet the needs of these individuals are markedly different. This is like trying to find out how to take care of patients in a hospital with no knowledge of what diseases the patients have, or giving patients with different cancers the same treatment. This analogy may seem extreme, but I would argue that it seems extreme only because we now know so much about cancer. If nursing homes and other long-term care services have been carefully studied, in ten years we will be treating those with dementia very differently from others who now share their rooms in nursing homes.

4. We do not really know precisely how much the Federal Government is spending on health services research for those with dementia. Carol O'Shaughnessy at the Congressional Research Service recently did a telephone survey of executive agencies supporting such research. She found the National Institute on Mental Health, the National Institute on Aging, and the Administration on Aging each were supporting several projects. The Health Care Financing Administration is going to include a

new measure of mental status in one of its long-term care case-mix reimbursement demonstration projects (and may start another next year). The figures are not exact, but we estimate that 1.3 to 2 million dollars will be spent on these projects in fiscal year 1986. This compares to 4.4 billion dollars paid by the Federal Government (and 4.1 billion dollars paid by States) for nursing home care alone (estimates for individuals with dementia nationwide). Total costs of the illnesses were estimated at 24 to 48 billion dollars for 1985, including direct payments from patients and their families and projections of informal care costs.

5. How to spend dollars depends on who is spending them. I was asked a similar question by the State of California, and my advice was to concentrate on education (through school and higher education systems); certification of hospitals, clinics, and long-term care facilities; and licensing of health professionals. These are functions that are most heavily influenced by State government policies.

The Federal Government can best do those things that States and nongovernment groups cannot do. This includes biomedical research, and much of health services research. These research functions could build upon experiments carried out by private firms (nursing homes, hospitals, etc.) but the entire nation benefits from Federal involvement because there is a higher probability of nationwide dissemination of the results and a basis for coordination (to reduce duplication of effort and encourage studies that build one upon the other rather than independently generating incompatible data sets).

Federal health programs, particularly Medicare and Medicaid, constitute another area that can only be addressed at the Federal

level. Some believe that in the next few years, the emphasis will be on how to spend the same Federal dollars for better care or for more people, rather than expansion of the dollars available. If this is the case, I believe it is time to experiment with new care methods, to evaluate what works, and plan to incorporate that into future health program planning. Others disagree, and urge expansion of current health programs to cover long-term care despite the increased costs. They argue that overall costs would drop because the health system as a whole would be more efficient. If you agree with this, then the emphasis would be on finding ways to carefully expand existing programs to cover long-term care, perhaps along the lines of the suggestions made by the Harvard group, by Karen Davis and Diane Rowland in their new book on Medicare, or by the American Public Health Association. Reports soon to be released by the Brookings Institution (on long-term care financing) and the Secretary of Health and Human Services (on catastrophic health care financing) may also set the stage for such political choices.

Family support services should be studied, but direct funding of family support is not a natural "fit" for federal intervention (with a few exceptions I will mention below). ADRDA and numerous other family support groups have sprung up across the country with little assistance from government, and I suspect that adding Federal funds would not necessarily improve the process. Special attention to two types of groups is, however, appropriate. First, those who have no families need help from local, State, and Federal Governments. Second, those who are in minority groups or have reduced access to existing support groups because of low economic status could use help in transportation and other services that could allow them to set up their own groups or participate

in existing ones. An important point relevant to minority groups and those living alone is that there are generally informal care networks at work even here, and any government programs should supplement rather than supplant them. Finally, some parts of family support do fit well with existing Federal programs. Availability of personal care, home care, day care, and counseling are each in part dependent on Federal monies, generally either through Medicaid or Federal block grants to States. Both Medicaid and block grant programs are administered by States, but subject to Federal guidelines.

Regarding education, the Federal Government is central to training those who will train others. It is also logical to coordinate the dissemination of information derived from nationwide research (on basic and clinical research as well as public health and service delivery) at the Federal level. This is relatively inexpensive, particularly if the mechanisms take advantage of existing national organizations such as ADRDA

6. The options in paying for patient care are especially important as they affect financing long-term care. Options range from pure private funding to use of Federal influence to encourage activities of individuals and corporations to direct public subsidy under expanded health and social service programs. Without detailing the options here, I will refer you to our forthcoming report (which has a chapter on this) and another paper that will soon be available that was prepared for our workshop on financing by Karen Davis and Patricia Neuman of Johns Hopkins University. Each of these explains the full range of options and some advantages and disadvantages of each.

It is clear that no one knows which options are likely to work in practice. I strongly encourage consulting with families, nongovernment organizations, private insurers, and State governments before engaging on a major reform of long-term care financing. Each of these groups can identify weaknesses of different approaches.

The main point of consensus at our May workshop was that long-term care financing is an important growing problem for public policy. The other point of agreement was that there is no agreement about what to do about it. Much of the disagreement is possible because so little is known about projected costs, and current cost estimates are not trusted. The other main source of disagreement is about the role of government. The ideological debate is unlikely to be resolved, but it is my own judgment that much of the disagreement would evaporate if we knew what to do and how much it would cost. That is, I perceive the ideological barriers to solving the problem as less important than the factual uncertainty and lack of agreement about how to reduce it.

A final point about financing long-term care. There are many who worry that Alzheimer's disease will receive special attention in any attempts to reform long-term care. They worry that those with one disease (or one set of symptoms) will receive special treatment. I want to make clear that there is no reason that long-term care reform should be done only for a special group, but reform that does not take the special problems of individuals with dementia into account is bound to fail. It will fail because those with dementia constitute the majority of those needing long-term care for months to years. There has been a reluctance to study those with dementia specifically, and the stated reason for this avoidance has been that long-term care should be reformed

for everyone. I agree with the conclusion, but not the logic or the antecedent. Failure to address the specific needs of those with dementia is one of the fundamental flaws of the current long-term care system.

7. There was no consensus at either of the workshops about coordination of efforts. In fact, there was a notable lack of consensus, and this is one of the problems. I believe there is general agreement about a few points, however. First, no one agency can do all the work required. The key agencies for basic research are the NIA, NIMH, and NINCDS; those for health services research are NCHSR, NIA, NIMH, AOA, HCFA, and the VA. The DHHS Task Force on Alzheimer's disease already exists to coordinate efforts among these agencies. If that Task Force has a weakness, it is not in a failure to coordinate efforts (which many agree it has greatly improved). The Task Force is composed of the heads of the Federal agencies supporting work in the relevant areas, and is ideally situated to allocate tasks and foster agreement and data sharing. It is not, however, by its nature or mandate well constituted to identify future priorities or emerging issues. These functions would best be served by outside experts who are closer to the realities of daily practice in science and service delivery.

An outside panel such as that included in one of the bills under consideration could conceivably identify future priorities and anticipate policy needs. I have several observations regarding such a board. First, the quality of what is done depends on who is appointed. This, in turn, depends in part on the appointment process. The suggested appointment procedure involves both the legislative and executive branches, and might well work, but what is to ensure overall balance of

an advisory group so appointed if there is no one line of authority for making the appointments. This may already have been anticipated, and there are overall guidelines for the characteristics of those appointed, but I wonder about the details of the appointment process not covered explicitly in the proposed legislation. I believe it would help to be more explicit.

I also wonder if one panel can realistically be expected to give advice on priorities in biomedical research, health services delivery, and issues related to financing of long-term care. Could there be two panels – one to advise agencies or the Task Force on how to best direct biomedical research, and another to set goals for health services research and delivery of care (that would report to the Secretary of HHS or the President)? There are also questions about where such an advisory panel should report: to one agency, the Task Force, the Secretary of HHS, the President, or Congress? I believe it is reasonable that any such council should write its reports free of influence from any agency or committee, and should submit its independent reports to the Congress and to the executive branch.

Reporting to the President or the HHS Secretary would likely make the recommendations more visible and robust, but reporting at this high level may have less immediate and direct impact on research agendas and daily practices in health and service programs. Reporting to NIA, NINCDS, or NIMH, on the other hand, makes the recommendations more likely to be immediately felt locally (assuming the directors of the agencies remain sympathetic), but agencies not directly involved would be less likely to follow recommendations. Perhaps a scientific council could

advise NINCDS, NIA, and NIMH, and a separate health services research and health services delivery council could report to the HHS Secretary or the President (with recommendations to be coordinated by the existing Task Force).

Outside experts would likely improve the ability to anticipate issues and articulate goals and objectives, but decisions must be made about whether there should be one or several such bodies, and about who to inform most directly. If an advisory structure for health services is set up, it should be staffed. If the advisory council is scientific, then it could be funded through NIH like other advisory councils; it will not likely require additional staff.

For health services research and service delivery, however, I believe it would be essential to have a minimal permanent staff. This is because there is so much going on across the country. Several States have reports on Alzheimer's disease, and many more have legislative programs or executive actions already taking place. ADRDA, the Family Survival Project, the French Foundation, and disease groups for Parkinson's disease, Multiple Sclerosis, Huntington's disease, head injury, and other disorders are all involved. Nongovernment organizations have a stake and are supporting activities through chapters, lobbying agents, and in State Governments. Professional organizations like the American Health Care Association, National Council on the Aging, National Association of Insurance Commissioners, National Association on Home Care, American Association of Homes for the Aging, American Association of Retired Persons, Health Insurance Association of America, National Conference of State Legislatures, National Governor's Association, American Public Welfare Association, Employee Benefit Research Institute, and many other groups have direct interest and

expertise. Keeping track of this ferment of activity has been a challenge for the OTA project, and would not be possible at all without a permanent staff with responsibility to survey the national scene.

Keeping track of developments is somewhat simpler in basic research, where the vast majority of support comes from the Federal Government, supplemented by the ADRDA, French Foundation, American Federation for Aging Research, and Howard Hughes Medical Institute (with other smaller private charities). Scientific research is also easier to track because the scientists supported and the national centers of excellence are fewer, and most of the important work is published in widely available journals.

8. The Veterans Administration is capable of doing longitudinal studies at several of its facilities, but not most of them. The VA has pioneered in studying nursing home care and in setting up geriatric evaluation units. It also has key efforts in training nurses, physicians, and researchers. Some VA facilities — notably several associated with medical schools in the Northwest, California, the mid-Atlantic region, and the Northeast — have a wide array of acute care, long-term care, family support, noninstitutional care and other services linked to a method of assessing patient needs. These facilities can make a unique contribution to the care of those with dementia, and can lead the way for other VA facilities and indeed are already beginning to provide a model of care for those outside the VA system.

In other areas (the majority of VA hospitals and other facilities), the VA can assist in diagnosis and medical treatment of eligible veterans. The VA is not a uniform system of care. There are dramatic

differences from facility to facility and region to region in the range and availability of services, particularly for non-service-related illnesses and long-term care.

9. Training must be divided into different sectors. Training of health professionals - physicians, nurses, social workers, physical therapists, speech therapists, occupational therapists, psychologists, an others - is key to the delivery of future care. The Federal Government is ideally situated to take information from the large Federal efforts in biomedical research and translate it into a form useful for teaching such professionals. The Federal Government also has a direct, but diminishing role in paying for medical and nursing education.

Equally important is education of nursing aides, family caregivers, and the general public. Materials for these groups much be tailored for a lay audience. ADRDA and the American Health Care Association have cooperated to develop a manual to be used by nursing home aids. There are many books available about daily care. One is a best-seller already,

Senator METZENBAUM [presiding]. Thank you, Dr. Cook-Deegan. Do I get by your last comment the implication that you think that that is a disproportionate distribution?

Dr. COOK-DEEGAN. Of course, from OTA, I cannot make a judgment, but I think the figures speak for themselves.

Senator METZENBAUM. I am particularly pleased to welcome our next witness. He is a new Ohio constituent, and that is important, but he is also very dedicated and knowledgeable in this field. He has been until recently on the faculty of Johns Hopkins University School of Medicine, as assistant professor of neurology and neurosciences. He was involved with basic research on Alzheimer's disease and with clinical care at Johns Hopkins Hospital.

Dr. Whitehouse was recruited by the University Hospital's board of trustees, and is in the process of moving to Cleveland now, which is a very brilliant decision on his part. He will be developing a model program for health care delivery for Alzheimer's disease victims and their families. He will be heading the Alzheimer's center with responsibility for research, for teaching, for the development of new specialized long-term care initiatives.

I am pleased that Dr. Whitehouse has adopted Ohio, and I am pleased that he is joining us here this morning.

Dr. Whitehouse.

Dr. WHITEHOUSE. Thank you, Senator. My family and I are looking forward very much to become citizens of Ohio.

As you have mentioned, I have been a biomedical researcher at Johns Hopkins University, focusing my research on understanding the neurobiology of this particular disorder. I will be moving to Cleveland, where my horizons will be broadened to developing innovative health care programs for victims of this disease in Ohio, but also to develop national models.

I will address my comments to the interface between basic and behavioral or social research, both very important areas that I think are included in many of the bills that are before you.

My message is twofold. It is one of ignorance, but it is also one of hope. Ignorance, in that we really at a very fundamental and biological level, do not understand what Alzheimer's disease is, and moreover, do not know how to care as a nation for the victims of this disorder—and hope, because in the areas of science and biology that will help us answer these questions, there is a tremendous spirit of inquiry which is developing.

Let me discuss basic research first, and then behavioral research.

First, basic research in Alzheimer's disease is underfunded, any way you want to compare it. That is a message other people have been giving you. And it is also relatively inexpensive with regard to some of the other items that are being considered in this bill.

I urge the support of additional centers for the study of Alzheimer's disease. I urge you not to lose track of the fact, though, that the traditional program project grant, as developed by the NIH, will still be a major vehicle for supporting research in this area.

My special point, besides the fact that basic research is underfunded, is that the time is now. Neuroscience is in a tremendous period of intellectual growth. There are departments of neuroscience cropping up at major institutions. We have the techniques, we

have the tools to apply to Alzheimer's disease, if we have the resources to do it.

And finally, Alzheimer's disease would only be one of the beneficiaries of those kinds of research programs. If we understood more about Alzheimer's disease, we would understand more about Parkinson's disease, amyoltrophic lateral sclerosis, and other diseases that affect the brain in the elderly. There is no question that basic research targeted at Alzheimer's disease would increase our understanding of that disease, as well as many, many others of importance to this Nation.

Turning our attention to behavioral research, something that is relatively new to me, but it is clear, as you have heard from other people, that we have a fragmented, inequitable health care system that everybody recognizes needs change, not to discount the pioneering efforts of some of the individuals here who have participated in that system.

I think we need short-term changes in the Medicaid and Medicare legislation along the lines in Senator Metzenbaum's bill, and suggested by ADRDA. I think special focus on respite care is appropriate because that is consistently mentioned as a priority for victims families; and yet my theme would be we do not know how to deliver adequate respite care yet. Programs of developing respite care have to be started in a spirit of inquiry, where we are concerned about measuring whether respite care really serves the purpose for which it is intended.

But I think it is also important to recognize, as we approach behavioral research in this area, that there are major long-term problems with our health care system—and it is true for Alzheimer's victims as well as other elderly individuals with different diseases. We have a long-term care system which is primarily based on an acute medical model, physician dominated. We need to develop a health care delivery system which recognizes the chronic and progressive natures of Alzheimer's disease and that encompasses a broader psychosocial perspective.

I would urge the relaxing of the funding and relaxing of regulations so that model programs can develop, model programs of all different kinds, that focus on continuum of care, that focus on the fact that victims of this disorder require different programs at different stages of illness, that need to be integrated in a way that they are not currently; In fact, the long-term institution that a victim may require if he or she gets that far in the illness may be an institutional hybrid of nursing home and boarding care facilities. They may be institutions that we as yet do not have as part of our system. Major changes, are I think, in the works.

So in conclusion, my message is one that we have a lot to learn, both about the biological and the behavioral effects of Alzheimer's disease. But there are resources, and there is hope that the Federal Government will now focus more effort. It is difficult for all human beings, perhaps politicians most of all, to take a long future view, but we really need to take that view in this area.

The Federal dollar is important not only because of its size, but also because of its symbolism. Where you put money, other money will follow.

The leaders of this Federal enterprise are here, and in fact, perhaps you are the wrong audience for my comments Senator Metzenbaum. I commend you for your efforts, I hope that you will continue in that cooperative spirit. I certainly wish you luck in your efforts to convince your colleagues and the administration.

Thank you.

[The prepared statement of Dr. Whitehouse and responses to questions submitted by Senator Metzenbaum follow:]

TESTIMONY OF

PETER JOHN WHITEHOUSE, M.D., Ph.D.

BEFORE THE SENATE COMMITTEE ON AGING

Thank you for the invitation to address your committee concerning Alzheimer's disease (AD) and related disorders, a subject of vital importance to the health and well being of our nation. My name is Peter John Whitehouse, M.D., Ph.D. I am a neurologist and neuropsychologist with additional training in psychiatry, neuropathology, and neuroscience. Until recently, at The Johns Hopkins University School of Medicine, I focused on care of individual patients and basic research into the biology of this devastating illness. I have also been involved in research involving positron emission tomography and clinical trials of drugs that may more effectively treat the psychiatric and cognitive symptoms of this disorder. At John Hopkins, I have been affiliated with the Alzheimer's Disease Research Center, funded by the National Institute on Aging. I am currently in the process of moving to University Hospitals of Cleveland to assume directorship of a major initiative in developing innovative health care programs for victims of these disorders and their families. In addition to being Director of the Alzheimer Neuroscience Center, I am Director of the Division of Behavioral Neurology at Case Western Reserve University. I am a member of the Office of Technology Assessment Panel on Alzheimer's Disease, and

I have had the opportunity to testify for Senator Grassley here in Washington. I have also been involved in the state legislative responses to the problem of AD in Ohio, Maryland, and Kansas. I have recently been a reviewer for the Centers for Excellence in Alzheimer's Disease program funded by the National Institute on Aging.

My talk will be based on two premises: first, that we do not know at a fundamental level what AD is; and, second, that, as individual care providers but particularly as members of a health care system, we do not know how to adequately care for patients with this disorder. Because of my emphasis on the lack of knowledge that we have concerning this condition, I will focus my comments on research, both biological (into the basic nature of this disorder) and behavioral (into the design of health care for victims of this disorder). I will not specifically discuss the major problem of adequately educating both lay and professional individuals concerning the problem of AD.

Biological Research

Although AD was described in 1907, it is only recently that we have become to understand the heterogeneity of the behavioral and biological changes that occur in AD and related disorders. It is even possible, in fact perhaps likely, that different diseases are currently masquerading under the single term, "Alzheimer's disease". Given the number of individuals affected by this condition, basic research is dramatically underfunded. This statement is particularly evident when per capita spending for research in AD is compared with that for cancer and

vascular disease. Yet, basic research is not underfunded for lack of new scientific approaches and methods. Neuroscience has grown tremendously in the last several years and offers a variety of new techniques that can dramatically increase our understanding of the disease and bring us closer to finding its cause and prevention. Although I strongly support the establishment of more Alzheimer's Disease Research Centers, certain qualifications to my support exist. There is a danger that a small number of centers will channel too much research funding to themselves, underserving wide parts of the country. I would propose more, perhaps smaller, grants to permit the designation of Centers for Excellence for appropriate institutions around the country. It is evident from my participation in the review process of center grants that there are many institutions that are currently not funded as centers that do provide excellence in research, teaching, and health care. These center grants would allow the institution to develop a core facility and to attract additional funding from private and state sources. The RO1 grant mechanism should be preserved as the major vehicle for funding research on AD, although certain collaborative projects will require funding at the Program Project level as well.

It is important to emphasize that any gains in basic understanding of the biological mechanisms of AD will undoubtedly lead to major advances in our understanding of other related disorders. For example, close relationships exist between AD and Parkinson's disease -- another common disease affecting the elderly that can be associated with

dementia. Research on AD will contribute to our understanding of the fundamental neurobiological mechanisms of aging. Moreover, such research will lead to better understanding of relationships between brain dysfunction and behavioral disturbances in other neurological and psychiatric disorders.

Behavioral-Social Research

The victim of AD and his family are presented with a confusing health care system that does not adequately meet their needs. At times, our health care system contributes to, rather than alleviates, the suffering of families. Rather than the ideal integrated health system that provides care for victims appropriate to their needs and stage of illness, we have a health care system characterized by fragmentation. Short-term fixes to our current system for AD victims are needed as well as a careful appraisal of long-term health needs, not only of victims of this disorder, but of the elderly in general. Such changes need to occur in an environment that recognizes that optimal health care models by no means are obvious. The development and evaluation of experimental programs should be encouraged.

Short-Term Considerations

In the short term, procedural changes in legislation involving Medicaid and Medicare should be made along the lines included in Senator Metzenbaum's bill and as recommended by the Alzheimer's Disease and Related Disorders Association. These changes would, for example,

eliminate discrimination against victims of AD, particularly those under the age of 65, and permit financial assistance to families of AD victims who provide so much of the care of the affected individuals. Respite care is consistently singled out by families as a high priority. It is so important to remember that, although what we can do for an individual victim directly is limited, our ability to help the family can be dramatic. Obviously, this process of helping the family indirectly aids the victim.

Long-Term Considerations

The consequences of our aging population on our medical system will continue to be dramatic. Programs established by the Federal Government to assist in financing health care of the elderly do much more than determine patterns of reimbursement -- they fundamentally affect the development of health care institutions. The acute medical model of health care has been applied too long to the chronic bio-psychosocial problems of the elderly. Health care research needs to be supported so that innovative and more cost-effective forms of long-term care can be developed (home care, day care, respite care, institutional care). Medicare waiver programs and other model programs need to be supported in the setting of academic research, where the success or failure of a program can be judged on objective criteria rather than on subjective opinions. The ideal long-term care facility for AD victims may be a hybrid of the boarding home concept and the traditional nursing home. Quality assurance and regulations of these novel

programs will eventually need to be developed after model programs have suggested appropriate new forms for institutional and home care.

Conclusions

I do not profess to know what you want for your country, nor how you as individuals wish to spend the later stages of your lives. I want to live in a country whose vitality and viability are measured by our ability to save lives, not destroy lives. Society needs to recognize the productive contributions of elderly citizens and to assist them in their declining years. The magnitude of the problem of AD and related disorders demands an active role by the Federal Government. In a time of concern about health care costs, our job is to determine how to use our health care dollar more effectively.

ANSWERS TO ALZHEIMER'S QUESTIONS

Peter J. Whitehouse, M.D., Ph.D.

RESEARCH FUNDING

Targeting of Funds: I agree with the development of further Alzheimer's Centers, but I believe that it is very important that regular program projects and R01's also be strongly supported. Regarding specific areas of research target, I believe characterizing the clinical and biological heterogeneity of Alzheimer's disease is important. Whether Alzheimer's disease is one or several diseases with difference causes and treatments needs to be addressed vigorously. Further characterizing the nature of the neuronal populations of nerve cells that die in the disease continues to be important and to attempt to relate the disease in the brain to the clinical symptoms of the patient. Further molecular biological dissection of the composition of the primary pathological features of Alzheimer's disease; namely, neurofibrillary tangles and senile plaques, is also very important.

PROMISING BIO-MEDICAL RESEARCH LEADS

It is very important that the genetic risk in Alzheimer's disease be further defined. If we can study cases in which there appears to be a clear-cut genetic mechanism of transmission, such as autosomal dominance, we can begin to apply the molecular biological approaches which have recently led to the successful localization of the chromosome containing the abnormal gene in Huntington's disease. I believe, however, that we are still quite far from the development of a comprehensive enough understanding of the disease to be talking seriously about the development of cures.

BIO-MEDICAL RESEARCH

Successes of current research efforts: The increase in research funding has led to a tremendous explosion of knowledge concerning Alzheimer's disease and related disorders. We are still very far away from understanding the primary cause and developing effective treatments for this disease, however. The research has excluded, to my satisfaction, some of the more simplistic models of causation. In my opinion, it is clear that the alumininum and slow virus stories have been exaggerated, though the exploration of these hypotheses has led to further basic understanding about how metals and novel infectious particles may contribute to pathology in the nervous system. Currently, there are few signs that there are any effective biological treatments on the horizon. Again, the development of these treatments will depend on developing a comprehensive model for how nerve cells die in this disorder. I do believe that there are new and innovative ideas being developed in terms of psycho-social treatment of patients with these disorders, including special care units and home respite and day care units.

ANSWERS TO ALZHEIMER'S QUESTIONS (Cont)

HEALTH SERVICES

Critical needs for patient and family services: The families identify respite care of several different varieties as being a primary need for them, although the nature of the most effective respite care system needs to be studied carefully. I believe that a more comprehensive assessment of patients and how their individual of deficits affect them in their home environment is also critical.

COMMENTS ON OTHER ISSUES

Special Priorities: 1) Molecular biology of Alzheimer's disease, 2) Establishing a genetic mechanism, 3) characterization of populations of nerve cells at risk.

Special Gaps: Health services research.

Senator METZENBAUM. Thank you, Dr. Whitehouse.

Dr. Buckwalter.

Dr. BUCKWALTER. Good morning. I am Kathleen Buckwalter, from the University of Iowa College of Nursing, and I am very pleased to testify this morning before the Subcommittee on Aging on an issue as critical to American families as Alzheimer's disease.

I have studied the four bills—S. 174, 1736, 1835, and 2183. Although each of these reveals great concern for the problem of Alzheimer's disease and contain a significant number of interventions and important ideas, I believe that none of them adequately address the need for a systematic approach to research and training in the areas of Alzheimer's disease patient care and management.

In my statement today, I hope to convey a sense of the needs and opportunities which exist to assist Alzheimer's victims and their families. I will also highlight briefly what I believe to be the priority areas which need investigation in order to make progress in caring for individuals with dementia.

To date, there has been a real dichotomy in research on Alzheimer's disease. The bulk of the research has been I believe properly directed on a long term, biomedical future-oriented approach designed at uncovering the cause of the disorder and thereby identifying strategies for cure and prevention. In the meantime, very little study has been directed toward improving the situation confronted by the 2 to 3 million victims afflicted with Alzheimer's disease as well as their family members.

What is needed is an applied services research focus on Alzheimer's disease which has more of a here-and-now orientation and which focuses on the development of research-validated clinical and services approaches to deal with current pressing needs of this population.

The development of appropriate, effective and safe services for the care and support of Alzheimer's disease victims and their families is a particular challenge because of the complex nature of the illness. In designing services and interventions, it has to be kept in mind that Alzheimer's disease is a progressive, inexorably deteriorating clinical course and that the anatomical and neurochemical changes that occur in the brains of its victims are accompanied by impairments in behavior such as wandering, agitation, verbal and physical outbursts, cognitive impairments, most particularly memory and orientation changes, emotional disturbances such as depression, and impaired psychosocial functioning, such as stress among family members and burnout among both formal and informal caregivers.

This means the nature of the services, the range of those services, the amount and the types of providers needed by patients and their families during the full course of this unpredictable illness can vary dramatically at various stages of the illness.

Second, an understanding of the problems of wandering, sleeplessness, agitation, suspicion, depression and other behavioral and emotional consequences of Alzheimer's disease illuminate the nature of the chronic and difficult stressors with which caregivers live.

The nature of the clinical progression of this illness and its consequences to the patient and family is also the key to the way in

which research and training issues should be addressed. That is, I think we must focus on the development of interventions and services which are designed to control the changing mental, psychological and behavioral problems which are the fundamental characteristics of Alzheimer's disease. What can we do to handle the behavioral and emotional consequences of this devastating disorder? We must design interventions and service delivery patterns which assist caregivers to maximize patient functioning, and at the same time, minimize emotional costs to themselves. We need to help these individuals to cope with the pervasive feelings of bereavement, guilt, anger, frustration, and depression that they face in their caregiving efforts.

The current services research knowledge base is sparse and somewhat fragmented, and does not always represent the state of the science.

For example, many of the current studies are not well grounded theoretically. They lack control groups or comparison groups. They are cross-sectional rather than longitudinal in their design, and they employ a wide variety of imprecise instruments that make it impossible to generalize findings across studies.

Similarly, even the so-called model programs are difficult to evaluate in that they were not designed to be true research models, and they are impossible to compare from program to program.

Also, these programs often have an inherent bias in their evaluation component in that the program providers themselves are doing the evaluation, and naturally, they believe their own program to be the best.

We must apply rigorous scientific methods to make effectiveness determinations for both program and treatment approaches.

An additional problem for consumers, researchers, clinicians, and legislators is that services such as respite, home health care, family support, and outreach are assumed to mean something quite specific, when in actual practice, they vary a great deal in terms of the expertise of the provider, the environment in which they are conducted, and the therapeutic emphasis or lack thereof.

A fundamental concern that I have as a service provider and consumer advocate is the lack of clearly defined research-validated approaches and training that can lead to a situation where a consumer of services unknowingly places himself or the family members in a situation which, at best, they do not get what they expect, and at worst, may in fact be harmful.

It is my belief, along with many of my colleagues in the service provision area, that the highest priority should be given to long-range applied services research and development strategies, coupled with the identification of services research and development sites.

Legislation to establish this type of intensive approach should provide for both individual project grants as well as more comprehensive multiproject program grants for a truly integrated strategy in contrast to some of the current piecemeal fragmented efforts.

I believe the Federal Government should make a serious, full-fledged commitment to addressing these issues.

But I need to conclude my remarks on an optimistic note, because I also believe that with the proper national commitment, a

great deal can be accomplished. We now recognize that major gaps exist in our current knowledge base about specific, optimal interventions and services for dementia patients and their families. However, we also have good evidence to believe that an aggressive research program offers the promise of developing ways in which to manage the behavioral, emotional and cognitive symptoms characteristic of this dread disease, to reduce excess disability, and to alleviate many of the short- and long-term adverse consequences to family members who assume the caregiving role.

Senator GRASSLEY. Thank you, Dr. Buckwalter, and I am glad I was able to hear most of your testimony, if not all of it. I am sorry for the other two; as I explained before, I was away, asking questions of the Ambassador for our international trade.

[The prepared statement of Dr. Buckwalter and responses to questions submitted by Senators Grassley and Metzenbaum follow:]

Testimony of Kathleen C. Buckwalter, Ph.D., R.N.

Associate Professor

University of Iowa

College of Nursing

before the

Subcommittee on Aging

Committee on Labor and Human Resources

United States Senate

July 22, 1986

Good morning Mr. Chairman and members of the Committee. I am Dr. Kathleen Buckwalter of the College of Nursing at the University of Iowa. I am very pleased to be here to testify before the Aging Subcommittee of the Committee on Labor and Human Resources on an issue as important to American families as Alzheimer's Disease.

I have studied the four bills S. 174, S. 1736, S. 1835, and S. 2183. Although each reveals great concern for the problem and contains a significant number of interventions and important ideas, I believe that none of them -- either individually or collectively -- addresses the serious absence of support for a systematic approach to research and training in the areas of Alzheimer's Disease patient care and management.

In my statement today, Mr. Chairman, I am going to try and convey a sense of the needs and opportunities which exist as you consider ways in which to assist Alzheimer's victims and their families. I will also highlight what I believe to be the priority areas which need investigation in order to make progress in caring for individuals with dementia.

There has been a dichotomy in research on Alzheimer's Disease (A.D.). The bulk of research has been directed, properly, on a long-term, bio-medical future-oriented approach designed at uncovering the cause of the disorder and thereby identifying strategies for cure and for prevention. In the meantime, very little study is being directed toward improving the situation confronted by the approximately 2 million older people now afflicted with the disease and addressing the needs of these victims and their families. What is needed is an applied services research focus on A.D. which would be present-day oriented and which would focus on the development of research validated clinical and services approaches to alleviate the immediate needs of these people. New legislation should be developed to target the immediate need in this area.

The development of appropriate, effective and safe services for the care and support of A.D. patients and their families is a real challenge to us all

because of the complex nature of the illness. In designing services and interventions, it must be kept in mind that A.D. has a progressively downward clinical course and that the anatomical and neurochemical changes that occur in the brains of its victims are accompanied by impairments in behavior (e.g., wandering, agitation); cognition (e.g., memory, orientation); emotions (depression); and psychosocial functioning (such as family stress and burnout). First, this means that the nature of services, the range of services, the amounts and the providers of services needed by patients and their families during the full course of this illness can vary dramatically at different stages of the illness. Second, an understanding of the problems of wandering, sleeplessness, agitation, suspicion, depression, etc. illuminate the nature of the chronic stressors that caregivers live with.

The nature of the clinical progression of this illness and its consequences to the patient and family is also the key to the way in which research and training issues should be addressed. That is, we must focus on the development of interventions and services which are designed to control the changing mental, psychological and behavioral problems which are the fundamental characteristics of those with A.D. In addition, we must design interventions and service delivery patterns which assist caregivers in maintaining their patient at a maximum level of functioning, but which also help caregivers cope with their own feelings of bereavement, guilt, anger and frustration.

The current services research knowledge base is sparse. To date, little services research has been undertaken and what little has been conducted is scattered, piecemeal and does not always represent the state-of-the-science. From a research perspective, the majority of current studies can be critiqued on the following basis:

- they are largely atheoretical;
- they have inadequately attended to matters of comparison;
- they do not have adequate time for follow-up; and
- the instrumentation is crude and non-cumulative.

A major problem with many so-called "model" programs which makes them difficult to evaluate is that they were not designed as true research models and they are both difficult to evaluate and impossible to compare with other programs in terms of their effectiveness.

An additional problem for consumers, researchers, clinicians and legislators is that services such as respite, home health care, family support, and outreach are assumed to mean something specific, when in actual practice, they vary a great deal in terms of the expertise of the provider, the environment and the therapeutic emphasis or lack of any real intervention being applied. A fundamental concern that I have is that the lack of clearly defined research validated approaches and training can lead to a situation where consumers of services unknowingly place themselves or their family member in a situation which, at best, does not do what they expect and, at worst, is harmful.

While tremendous gaps exist in the research knowledge base, there is also a feeling of excitement and opportunity in the field. This is so for a number of reasons. First, there are numerous annecdotal reports from caretakers and clinicians of positive experiences with various behavioral management techniques such as those described in the "The 36 Hour Day" (Mace and Rabins, 1981). Second, studies which focus on different aspects of caregiving, including the nature of caregiving activities, stresses, and the coping mechanisms used by caregivers, are providing important new information which can lead to the development of new interventions. Finally, and in many ways the most exciting, have been persistent reports from clinicians of successes in reversing what has come to be called "excess disability" in Alzheimer's Disease patients. Excess

disability is the circumstance in which the functional level of the individual is substantially below what would be expected strictly on the basis of the severity of the dementia alone.

It is my belief, along with many of my collegues, that the highest priority should be given to a long-range applied services research and development strategy coupled with the identification of several services research and development sites so that the following seven critical issues can be addressed through high-quality research:

1. The optimal range of community and institutional services relevant to Alzheimer's disease in terms of design, staffing, timing of use during the progression of the disorder, mix, and coordination with other services.
2. The best methods of delivering services such as, outreach, comprehensive assessment, case (care) management, out-patient treatment, home health care, respite care, adult day care, partial hospitalization, and nursing home care.
3. The ways in which formal support services provided by health care professionals can be combined with informal support interventions provided by family, friends and neighbors through progression of illness.
4. The efficacy of new services for Alzheimer patients at different stages of disease.
5. The ways in which family caregivers can be sustained through interventions to reduce psychological, social and stress-induced physical problems.
6. The efficacy of various mental health treatment modalities that health care professionals draw upon to treat the mental problems (memory and intellectual dysfunction), the behavioral difficulties (agitation,

wandering, outbursts), and psychological symptoms (depression, delusions) that comprise the major disturbances of function in Alzheimer's disease.

7. The utility, configuration, and deployment of professionals applying treatment modalities and care for the individuals with Alzheimer's disease (e.g., the optimal role of psychiatrist, psychologist, social worker, mental health nurse, etc.).

Legislation to establish this type of intensive approach should provide for support of both individual project grants, as well as more comprehensive, multi-project program grants for an integrated strategy, in contrast to the current piecemeal, scattered efforts. Sites addressing these research issues would have an added contribution through their ability to provide the most sophisticated, state-of-the-science service delivery approaches to A.D. victims and their families.

The Federal government should make a serious full-fledged commitment to addressing these issues. This can only be accomplished through the allocation of sufficient resources to conduct such research.

I want to conclude on an optimistic note because with the proper national commitment a great deal can be accomplished. It is widely recognized that major gaps exist in our current knowledge base about specific, optimal interventions and services for dementia patients. However, we have sufficient evidence to believe that an aggressive research program offers the promise of developing ways in which to manage many of the behavioral, emotional and cognitive symptoms characteristic of the disease; to reduce excess disability; and to alleviate many of the short- and long-term adverse consequences to family members who assume the role of caregiving.

Mr. Chairman, I thank you for the opportunity for testifying on the services research needs of A.D. patients and their families. I shall be pleased to answer any questions that you and the members of the subcommittee may have.

5

QUESTIONS FOR DR. KATHLEEN BUCKWALTER FROM SENATOR METZENBAUM REGARDING ALZHEIMER'S DISEASE

(1) **HEALTH SERVICES RESEARCH**

THE PROPOSED LEGISLATION IN AT LEAST ONE OF THE BILLS DOES MANDATE HEALTH SERVICES RESEARCH. I ASSUME YOU CONSIDER THAT TO BE A HIGH PRIORITY -- AS HIGH A PRIORITY AS BIOMEDICAL RESEARCH?

(2) **ASSESSMENT**

DO NURSING HOMES HAVE UPON ADMISSION, ADEQUATE ASSESSMENTS OF THE FUNCTIONAL ABILITIES OF A PATIENT WITH ALZHEIMER'S, AND IS THERE A PLAN FOR MAINTAINING THESE ABILITIES AS LONG AS POSSIBLE?

DO NURSING HOMES NEED A STANDARDIZED ASSESSMENT INSTRUMENT? AND TRAINING ON HOW TO MANAGE PATIENTS WITH FUNCTIONAL LIMITATIONS? HOW DO YOU RECOMMEND IMPROVING THE SITUATION?

(3) **IDENTIFYING THE ISOLATED VICTIM**

WHAT MECHANISMS ARE THERE FOR IDENTIFYING THE ISOLATED OLDER PERSON WHO MAY BE A VICTIM OF ALZHEIMER'S, BUT HAS NO FAMILY TO CARE FOR HIM OR HER? WHO CAN HELP GET THE CARE NEEDED?

(4) **PROTECTIVE SERVICES**

IN THE TV SHOW, AMOS. MANY OF THE NURSING HOME PATIENTS HAD THEIR INTELLECTS INTACT BUT WERE FRAIL AND DEPENDENT, AND VULNERABLE TO ABUSE. WHAT PROTECTION IS THERE FOR DEMENTED VICTIMS, ESPECIALLY IF THERE IS NO FAMILY NEARBY?

(5) **FEE**

HOW DO YOU FEEL ABOUT FEES FOR SERVICES SUCH AS DAY CARE AND RESPITE CARE FOR FAMILIES WHO CAN AFFORD TO PAY?

September 8, 1986

Response to questions from Senator Metzensbaum by topic

1. Health Services Research

As I stated in my testimony I believe both biomedical research and health services research are necessary and important, and difficult to compare. Certainly we need continued support for future-oriented, long-term biomedical research efforts to find a cause and cure for the devastating affliction of Alzheimer's disease. But we also need equally vigorous support for health services research efforts to deal with the here and now, very real psychosocial, economic, and functional crises confronted by Alzheimers victims, their families, and caregivers.

2. Assessment

The assessment questions posed cannot be answered definitively at the present time and clearly illustrate the need for health services research to address these important issues in nursing home settings. A recent review of the literature conducted by a colleague, Dr. Meridean Maas, and me showed the clear cut need for the development of data-based functional assessment tools in long-term care settings. To meet this need for research purposes (in an investigation of functional abilities of SDAT patients in traditional integrated settings compared to those in special care units) Dr. Maas and I developed the attached instrument. Such beginning tool development efforts clearly require additional testing and refinement and psychometric development.

Certainly, we need to be able to accurately assess the functional capacity of Alzheimer's patients so that we can develop appropriate treatment plans.

Nursing home personnel and other caregivers all need training to enable them to manage patients with the functional limitations, behavioral disturbances, and emotional problems that accompany Alzheimer's disease in the best possible manner. Only through research can we establish the knowledge base upon which such training materials can be developed and thus the delivery of services enhanced.

3. Identifying the Isolated Victim

In Iowa we have ongoing demonstration and research programs funded collaboratively by the State Department of MH/MR/DD, the Administration on Aging (AoA), and N.I.M.H. to develop and evaluate mechanisms for the identification and referral of isolated victims in need of mental health, medical, and social services. A complete description of this program, "Mental Health of the Rural Elderly Outreach Project" was sent to Senator Metzenbaum's legislative aide in late July. Basically, the thrust of this program is to link area agencies on aging, community mental health centers, and a wide array of community based service providers in a deliberate outreach effort. Three identification sources (screening at outreach sites, case management network, and gatekeeps) help to locate and refer isolated victims (especially a problem in rural areas) for needed assessment and treatment efforts conducted by a multidisciplinary outreach team composed of a psychiatrist, nurse, and social worker.

4. Protective Services

My clinical experience suggests that we currently have insufficient protection for frail, vulnerable, dependent, and isolated elderly. As a newly appointed member of a governor's task force on elder abuse I am involved in systematic efforts to: 1) assess the incidence, dynamics, and consequences of elder abuse; 2) identify the public and private efforts underway to prevent elder abuse, ameliorate abusive situations, and provide services to victims; and 3) to recommend policy and service delivery changes as needed. These recommendations must be based on sound epidemiological data and services research.

5. Fees

We need to systematically evaluate the influence of offering different services and payment mechanisms on use patterns. How various fee structures impact on family stress levels must be determined. If fees for services (even for those who can afford to pay) contribute to, rather than reduce, family stress levels, then I believe they are counterproductive. However, at the present time fee-related issues have not been adequately studied.

The above responses are submitted by Kathleen C. Buckwalter, Ph.D., R.N., Associate Professor at the University of Iowa Collge of Nursing, Iowa City, Iowa.

Attachment

The University of Iowa
College of Nursing

Functional Abilities Checklist for
Institutionalized Alzheimer's Patients

Directions:

Name_____Unit_____Age_____Sex_____

Admission Date_____ Does the resident have Alzheimer's: No_____ Yes_____
If yes, is this diagnosis based on a: (check appropriate answer)

Comprehensive Evaluation: Yes___ No ___

History/Physical: Yes___ No___
List all Psychotropic and sedative medications this client presently takes:

_____

_____

Circle one rating for each item: 1 = never
2 = seldom (less than 7 times per week)
3 = frequently (daily)
4 = all of the time (multiple times per day)

Please note additional comments on the back page provided at the end of the checklist.

NOTE: When you complete the checklist, please refer only to behaviors of the patient that have occurred during the past week.

1 2 3 4 (1) Has difficulty in completing simple tasks on own, e.g. dressing, bathing.

1 2 3 4 (2) Requires supervision with eating.

1 2 3 4 (3) Uses utensils when eating.

1 2 3 4 (4) Eats food with fingers.

1 2 3 4 (5) Eats without assistance.

1 2 3 4 (6) Won't allow assistance with eating.

1 2 3 4 (7) Appearance is disorderly if left to own devices.

1 2 3 4 (8) Controls bowel function.

1 2 3 4 (9) Controls bladder function.

1 2 3 4 (10) Urinates in places other than stool, commode or bedpan/urinal.

1 2 3 4 (11) Has difficulty sleeping at night. (Check type of difficulty below.)

Trouble falling asleep _____

Wakeful during the night _____

Awakens prematurely _____

1 2 3 4 (12) Level of agitation increases at night.

1 2 3 4 (13) Needs to be watched so doesn't injure self, e.g., by careless smoking, leaving the stove on, falling.

1 2 3 4 (14) Destructive of materials around him, e.g., breaks furniture, throws food trays, tears up magazines.

1 2 3 4 (15) Accuses others of doing him bodily harm or stealing his possessions--when you are sure the accusations are not true.

1 2 3 4 (16) Threatens to harm others.

1 2 3 4 (17) Injures others. (explain)

1 2 3 4 (18) Invades privacy of others' possessions.

1 2 3 4 (19) Invades privacy of others' personal space.

1 2 3 4 (20) Exposes self in front of others.

1 2 3 4 (21) Performs sexual behaviors in front of others.

1 2 3 4 (22) Masturbates in public.

1 2 3 4 (23) Removes clothing at inappropriate times.

1 2 3 4 (24) Has sudden changes of mood, e.g., gets upset, angered, or cries easily.

1 2 3 4 (25) Loses things.

1 2 3 4 (26) Becomes confused and does not know where he/she is.

1 2 3 4 (27) Has trouble remembering recent event.

1 2 3 4 (28) Has trouble remembering nonrecent events.

1 2 3 4 (29) Spends time either sitting or in apparently purposeless activity.

1 2 3 4 (30) Wanders at night.

1 2 3 4 (31) If left alone wanders aimlessly during the day.

1 2 3 4 (32) Requires physical restraint. Type _____

1 2 3 4 (33) Requires chemical restraint. Type _____

1 2 3 4 (34) Wanders off unit if not watched.

1 2 3 4 (35) Leaves unit by self and returns.

1 2 3 4 (36) Wanders off unit to explore.

1 2 3 4 (37) Wanders off unit to elope.

1 2 3 4 (38) Runs into obstacles.

1 2 3 4 (39) Gazes ahead when walks.

1 2 3 4 (40) Gazes at floor when walks.

1 2 3 4 (41) Moans.

1 2 3 4 (42) Shouts or yells.

1 2 3 4 (43) Uses verbal communication appropriately to make needs known.

1 2 3 4 (44) Follows verbal directions.

1 2 3 4 (45) Uses nonverbal communication to make needs known.

1 2 3 4 (46) Nonverbal communication is appropriate to situational stimuli.

1 2 3 4 (47) Laughs appropriately.

1 2 3 4 (48) Irritable.

1 2 3 4 (49) Withdrawn.

1 2 3 4 (50) Flat affect.

1 2 3 4 (51) Angers appropriately.

1 2 3 4 (52) Holds eye contact when talking with others.

1 2 3 4 (53) Participates in appropriate relationships with others:

1 2 3 4 Staff

1 2 3 4 Residents

1 2 3 4 Others

1 2 3 4 (54) Interacts appropriately in groups.
(type_____)

1 2 3 4 (55) Prn medications are used for agitation, irritability.
(type_____)

from Senator Grassley

KITTY BUCKWALTER

(6) YOU MENTIONED THE CONCERN WITH SAFETY AND CONSUMER PROTECTION IN THIS AREA OF ALZHEIMER'S DISEASE. WOULD YOU PLEASE ELABORATE ON THIS?

We need research to determine the range of effective care options and to communicate the best models to the consumer and to warn them of potentially unsafe, harmful practices. Victims of Alzheimers disease and their families are often desperate and therefore potentially vulnerable to treatment "schemes" or unfounded "innovations", not unlike the cancer patient. At present, almost any facility can hang out a shingle advertising special care for Alzheimers patients; others may use physical and chemical restraints to "warehouse" patients under the guise of respite. With the proliferation of daycare, respite and special care units to meet increasing care demands, we need a systematic data base to guide their development and to assist vulnerable families in choosing optimal service programs.

KITTY BUCKWALTER

(7) YOU'VE HAD EXPERIENCE WITH RESEARCH PROGRAMS IN VARIOUS AGENCIES OF THE FEDERAL GOVERNMENT. WHAT WOULD YOU RECOMMEND WE CONSIDER IN IMPLEMENTING THE TYPE OF LEGISLATION YOU'VE DESCRIBED?

I've had a chance to review Senator Grassley's proposal and feel the five-pronged approach he has outlined, including continuation of the task force and establishing a clearinghouse, is an excellent step toward implementing the research issues I addressed in my testimony. In particular, titles 2, 3, and 4 present a reasonable research agenda. Together these titles allow coverage for all of the important areas of research related to Alzheimers disease in a comprehensive and equitable way. Based on my experience working with various federal agencies, I believe this research act would accelerate the ability of NIA to continue the fine job they're doing in epidemiology, diagnostic and assessment procedures; allow NIMH to expand its outstanding core of research looking at ways to manage behavior and the emotional aspects of Alzheimers disease and increase services research on effective ways to help family members; and finally will help NCHSR to develop much needed comprehensive data sets and cost estimates.

Senator GRASSLEY. We welcome Senator Hawkins.

Senator Hawkins, do you have an opening statement?

Senator HAWKINS. Thank you, Mr. Chairman.

I am pleased that you called this hearing today. We have been very pleased to work with you on developing the legislation. I share the public's concern and your concern and compassion for the victims of Alzheimer's disease and their families. We must do something that can help ease the burden that is currently borne almost entirely by individual families who have family members afflicted with this disease.

I believe the public's understanding and awareness of Alzheimer's disease has increased tremendously over the last few years; each time we have a hearing, I get many, many requests for transcripts. In Florida, we have many active chapters of the Alzheimer's Disease and Related Disorders Association, and they have played an important role in educating the public about the disease and the effect it has on between 2 and 3 million Americans that we know of.

I would be very pleased to see us come to some conclusion so that the family is not placed in a situation where their only choices are first, being emotionally drained by trying to provide all the care by themselves, or second, financially drained by trying to pay for others to provide for that care. It is a sad commentary that we have come to this, but we have seen many cases. The most celebrated case, I guess, would be in Florida, where Roswald Gilbert ended the life of his wife, who had been suffering from Alzheimer's disease. I think a tragedy of this kind points up again the urgency to keep some kind of solution, some kind of relief for the victims and the families.

As I was leaving another hearing just now, I mentioned to the Senator next to me that I was going to rush to a hearing on Alzheimer's disease, and he asked, "Where is it? I have a great interest in it." So I told him, and you will be having another Senator join you.

But every time you mention it, I think you see this urgency suddenly. And he said, "I have a personal interest." Now, that means even better than "interest." So I was encouraged that it is catching on.

The one thing that bothers me is the lack of information, the lack of research. We had a program this morning that someone sent me on AIDS and how fast we are coming to the identification of the virus, the national urgency of this, but at the same time, we need to be working, I think, just as fast on a solution to Alzheimer's disease.

I want to commend you, Senator, for the legislation you are working on. The subcommittee and all our staffs are pulling hard together to make sure that we can get the information and the research so that we can proceed to the next step.

I commend you for continuing your interest and look forward to some solution on this.

[The prepared statement of Senator Hawkins follows:]

STATEMENT OF SENATOR PAULA HAWKINS

"THE CARE OF PEOPLE WITH ALZHEIMER'S DISEASE

AND RELATED DEMENTIAS"

Mr. Chairman, I am pleased to join you at today's hearing. I know of your interest in this subject, your concern and compassion for the victims of Alzheimer's disease and their families and your efforts to develop legislation that will ease the burden that is currently borne almost entirely by those families.

The public's understanding and awareness of Alzheimer's disease has increased tremendously over the last few years. I know that in Florida we have several very active chapters of the Alzheimer Disease and Related Disorders Association who have played a very important role in educating the public about this disease which affects between two and three million Americans.

Through their efforts we have developed a better understanding of the effect that Alzheimer's disease has on not just the victims but also the families of the victims. The family should not be placed in a situation where their only choices are between being emotionally drained by trying to provide all care by themselves or financially drained by trying to pay for others to provide that care.

Last year in Florida, we had the celebrated case of Roswell Gilbert who ended the life of his wife who was suffering from Alzheimer's disease. An incident of this kind just points up once again the urgency to seek some kind of solution, some kind of relief for the victim and the family. Another tragedy is that a high proportion of the victims of this disease are elderly women who have outlived their husbands and have no family to care for them.

Congress' interest in this subject and their compassion for the plight of the victims and their families is apparent in the number of bills that have been introduced on this subject and the provisions that we have already enacted in an attempt to address this situation. I think that the bills that have been introduced by various members of Congress on this subject all have a common theme. They all reflect the concensus among us that society has an obligation to ease the burden by the family of the victim of Alzheimer disease. The lack of information and research in this area has complicated our task. We want to help, but we aren't sure how to best spend the limited financial funding. We need more information on which formal support programs, whether they are in nursing homes, hospitals, or daycare centers, show the most promise in meeting the needs of Alzheimer's disease victims and their families. We need an evaluation of these services.

The legislation that Senator Grassley is developing is a well thought-out method of providing Congress with the basic information and research that is needed so we can then proceed to the next steps which will provide Alzheimer Disease victims and their families with key services and supports so that the responsibility of care is shared.

Mr. Chairman, I look forward to working with you on this issue.

Senator GRASSLEY. Well, thank you, Senator Hawkins. And again, let me take 5 minutes, and then we will go to Senator Metzenbaum and then back to Senator Hawkins for questions.

I would like each of you to comment on something you have not heard yet, but our next witness, Dr. Helms, the Assistant Secretary for Planning and Evaluation, I think, is going to make the point that assisting in the provision of medical and social services needed by Alzheimer's disease victims raises generic long-term care issues. In other words, it is best pursued in the broader context, he would say, of how to provide care for people who are not able to care for themselves.

I asked a similar question of the first panel. Would you comment?

Dr. COOK-DEEGAN. Sure. I think I, in general, agree with that position. I think that starting from that position, though, there are a number of different directions to go. No. 1, when you talk about long-term care, it is really hard to figure out what it is that people are talking about specifically.

People with dementia constitute, as I said before, somewhere between 40 and 70 percent of those people who are in nursing homes. Now, those people who are in nursing homes are divided into two populations—those who are there for less than 3 months and those who are there for longer than 3 months.

If you look at the people who are there for longer than 3 months, which is where most of the catastrophic medical costs accrue—rather than for the short stay—then we are probably talking about somewhere between 60 and 70 percent of those people having dementia. So I do not see that you can address the problem of long-term care without directly addressing the needs of patients with dementia.

So I would agree that I do not think they are separable issues. I think it would help to try to specifically figure out what do patients who have dementing disorders need, that is somewhat different from what other patients might need, and I think other things would follow from that.

Senator GRASSLEY. Dr. Whitehouse.

Dr. WHITEHOUSE. I agree with Bob's statement. I think, as I said in my testimony, there is a need to look at short term solutions to some of the immediate problems that the families and victims face, but there is a need to reexamine at a strategic planning level our long-term care system in general, if we can call it a system. And it would be a mistake to isolate the dementias in general from that consideration.

Equally, though, it would be a mistake when one considers long-term health care for the elderly to not recognize that different diseases do have different characteristics and different needs. I think that is exactly what Bob said, and I think this view expresses our mutual background on the OTA panel as well as our personal opinions.

Senator GRASSLEY. Dr. Buckwalter.

Dr. BUCKWALTER. As I commented, I believe that the behavioral and emotional manifestations of Alzheimer's disease make it distinct from other chronic illnesses, and therefore the service needs are somewhat different from those for other long-term care popula-

tions and programs. We are dealing not only with the chronic deteriorating condition, with compromised functional ability and cognitive impairment in the patient, but the stressed family caregivers and inpatient providers who are dealing with manifestations of the illness, the wandering, the aggression, the agitation that I alluded to in my testimony, that makes it a unique situation. And I believe that it has unique demands, therefore.

Senator GRASSLEY. OK. A specific question to you, Dr. Buckwalter, on another point, but it is in regard to your reference to the concept of excess disability. You referred to it and defined it. My question is whether or not it really makes a difference in the case of Alzheimer's patients, and I would like to have you give me a case example from your own work of the difference that it makes.

Dr. BUCKWALTER. OK. Excess disability is the circumstance in which the functional level of the individual is substantially below that that would be expected simply on the basis of the brain damage, the damage from dementia alone.

I believe that it certainly makes a difference in the care of Alzheimer's patients. In my own practice, perhaps the most concomitant emotional disturbance we see is depression. And certainly with the judicious use of antidepressant medications and brief, 4- to 6-week limited psychotherapy in the early stages of the disease, we can improve the Alzheimer's victims' affect, make their lives less troubled, help them to enjoy life more. And this, of course impacts upon not only the individual, but their family members.

Senator GRASSLEY. One other point I would like to know if any of your research sheds light on is whether or not, after a person has gone so far downhill, they are affected by the environment very much—first of all, whether that is true, but how much difference to the individual do different care settings or care methods really make; and then, as a result, should research on care settings and methods be pursued, as would occur in provisions of some of the bills we are considering.

Dr. BUCKWALTER. Well, one of the things that we really do not know is the impact, especially in the later stages of the disease. I think it is an assumption that I would challenge that individuals in the later stages of the disease are not amenable to behavioral and environmental strategies. We do not know the degree of what we call their behavioral plasticity—that is, how much we can compensate using these various environmental and behavioral management strategies for the brain impairment.

My own practice and anecdotes in the literature, reports of other commissions, suggest that environment certainly does make a difference. But we need research to determine in what way—what is the effect on the functional ability; what is the effect on the cognitive impairment and decline?

I would add that I think a caring environment that is architecturally sound, that is environmentally designed, keeping the limitations of the illness in mind and its progressive course, leads to less of a decrease in functional abilities. We cannot stop the disease per se, but we can keep them functioning at a better level for a longer period of time. It certainly enhances family satisfaction and morale, and if you are in a caregiving environment where the caregivers are educated in an inpatient setting, they are going to use

less chemical and physical restraints with the Alzheimer's patients; and perhaps most importantly, until their death, will accord them respect and human dignity in that caregiving effort. And I do not think we can put a pricetag on those kinds of efforts.

Senator GRASSLEY. Thank you.

Senator METZENBAUM. Dr. Whitehouse, you have done considerable work in the field of molecular biology with respect to Alzheimer's patients. Have you seen any area that you consider a possible breakthrough, that you feel that there is any progress in that area at all?

I guess I am really asking you this: Do those who are the scientists involved in the area of research on the cause, have they made any headway at all?

Dr. WHITEHOUSE. That is an easy question to answer. Absolutely, there has been headway. I think, though, it is a very difficult question to answer in terms of, well, where is that leading any time in the near future.

I think that we have learned a tremendous amount about Alzheimer's disease. In fact, my perspective as a researcher on that is that the situation is getting more complex and not simpler. That is often the case when we devote our intellectual efforts. It's a problem we know more about it, but perhaps it is even more confusing than it was before.

But I think that is the mode we have to deal in scientifically now; we have to recognize our ignorance, not pursue unifocused kinds of approaches that you read about in the national media, which are not going to work, but broaden ourselves to encompass other disciplines.

But it is easy to say yes, and I could sit here and detail many, many scientific discoveries.

Senator METZENBAUM. Does Alzheimer's affect the total brain or just portions of it?

Dr. WHITEHOUSE. Just portions of the brain—although again, our inventory of those portions that are affected is increasing. I have a little theory that may relate to what Katie was saying. I think some of the parts of the brain that are involved with loving and caring and having some sense of being still a part of the family go later, and that all the things that we think of in terms of cognition, thinking, speaking go earlier.

So I think there are things that are affected at different rates, and I think those things correlate with the behavioral problems that the patients have at different stages.

Senator METZENBAUM. In an autopsy, do you see pathological changes in the brain?

Dr. WHITEHOUSE. You see pathological changes in many different areas. We are still using his same silverstain that developed to examine brain tissue to make a diagnosis, even 80 years later. So we certainly see pathology widespread, and that just makes it more complicated.

But again, as I said earlier, the tools and mechanisms that the field of neuroscience now has that it did not have 80 years ago, it did not have 8 years ago—in some cases, did not have 8 months ago—are really there to help us understand that complexity.

Senator METZENBAUM. Does the Alzheimer's patient's brain show up differently when you are doing a scan of the brain?

Dr. WHITEHOUSE. There is no diagnostic test in life for this disease. As Mr. Stone and others have recognized, Alzheimer's disease is a diagnosis of exclusion, where we say we cannot find any evidence of other tractible disease in life; therefore, it is likely to be Alzheimer's disease. About 90 percent of the time we are correct with that diagnosis of exclusion.

There are a lot of people working on diagnostic tests, and I think we are on the fringe of some discoveries there—and that is brain imaging, cerebrospinal fluid, blood tests, and the like—but nothing yet that is diagnostic in life.

Senator METZENBAUM. Dr. Buckwalter, I found your testimony very interesting because you indicated that none of the bills really do that which you think should be done, and I appreciated that comment.

I guess I would ask you if you could just zero in exactly on what do you think Congress should be doing legislatively, and what do you think others should be doing; and if you could tie it down very neatly, I would appreciate it.

Dr. BUCKWALTER. Well, if I could do that, I would probably be on the other side of the bench.

Senator GRASSLEY. Do not think about that for a while. [Laughter.]

Dr. BUCKWALTER. No, no. I am very happy where I am.

I did have a chance very recently to review the Research Act that Senator Grassley is proposing, and I thought that that five-pronged approach which continues the task force and which provides for a clearinghouse and titles II, II, and IV, which provide distinct challenges and charges to NIA, NIMH, and the National Center for Health Services Research, is a very effective way of implementing some of the research services needs that I addressed in my testimony, and I applaud that effort. I think it is an equitable distribution of the research services needs and will carry forward those areas of expertise that have already been established by the respective Federal agencies.

Senator METZENBAUM. Do you think we ought to target more of our funding for treatment of the patient, or more in the area of biomedical research?

Dr. BUCKWALTER. Well, I cannot escape from my own bias. I think both are obviously important, and I think we have, as I said, done a lot in the area of biomedical research with this future orientation right now; I think the time is right to divert additional resources to here and now services research needs that focus on the patients and their families.

Senator METZENBAUM. Thank you, Mr. Chairman, and I thank the panel.

Senator GRASSLEY. Senator Hawkins?

Senator HAWKINS. Comment on this, if you will. The Baptist Medical Center in Jacksonville, FL, has an Alzheimer's center that utilizes a multidisciplinary team of professionals to serve the Alzheimer's disease victims and their families. When the center opened, over 200 people signed up for the seminars and family support programs.

Do you have any comments on which professionals, in your opinion, should be included in the multidisciplinary team of professionals—social service professionals, religious counselors, grief counselors?

Do any of you have comments on that?

Dr. COOK-DEEGAN. I think, just to pick up on that a bit, the multidisciplinary team is becoming the norm, for several reasons. No. 1, almost all of the dementing illnesses last a very long time, and the needs of patients progresses the illness progresses. It is not just acute medical care, it is not just nursing home care. It is everything, and we need a lot of expertise.

I think it includes physicians, it includes nurses, it includes social workers, it includes nursing home aides, which often get neglected in this loop, it means psychologists, speech pathologists. There is a list of probably 30 types of training that would really benefit at some stage in the disease for any given patient. And I think they are all important. What is difficult is to come up with a mechanism for coordinating all those people in a particular center. But I think that is definitely the right approach.

Dr. BUCKWALTER. One of the things we do not know which needs to be addressed in the health services research is what is the optimal role for these different professionals.

I again support wholeheartedly the multiprofessional focus, but the utility, the configuration and deployment of these professionals applying their various treatment modalities to the care of Alzheimer's victims and families in a variety of settings has not been well defined or described, and we need more research in this area.

Dr. WHITEHOUSE. If I could just make a brief comment, I think it depends less upon the profession in this particular environment than the personal commitment that people make. I do not care if it is the physician, the psychiatrist, the internist, the neurologist, or what. There are some people who are attracted to this area, who feel personally committed; there are others that do not. Those are the people you have to find, regardless of their discipline.

Senator HAWKINS. Last week in the Senate, we passed the Domestic Service Volunteer Act, and one of the amendments that was offered was the Glenn-Hawkins amendment to require to an evaluation of the aspects of ACTION's program so we could provide volunteer support or assistance to families who were caring for their frail and disabled adult members.

Many of the ACTION programs, such as Senior Companions, Retired Senior Volunteer Program, and the VISTA Program, include a wide variety of volunteer services to family caregivers. But it is obvious we need more information about the role of the volunteer in assisting the family caregiver.

Do any of the programs utilize volunteers to assist the family caregivers that you know of?

Dr. COOK-DEEGAN. Specifically relating to ACTION, in fact, I have got on my desk in my office a manual that is being prepared by ACTION to train volunteer caregivers to provide in-home care, the kind of in-home respite that we have been talking about repeatedly today. They are drafting a manual so that it can be used nationwide, and it is based in fact on work that has been supported

by the Aging Instirute, the Mental Health Institute, and the Administration on Aging.

So it is one of those things that seems to be a success story, and they are already preparing something to take advantage of volunteers.

Senator HAWKINS. Thank you.

Senator GRASSLEY. Thank you, Senator Hawkins.

I had one more question for Dr. Cook-Deegan and two for Dr. Buckwalter, but because of time, I will submit those to you in writing.

Thank you all very much for your participation.

I would call our final panel. It consists of two distinguished witnesses. The first, I have already referred to—Dr. Robert Helms, who is the Assistant Secretary for Planning and Evaluation for the Department of HHS, and he is accompanied by Dr. Gene Cohen, who is Director of the Program on Aging at the National Institute of Mental Health and the Executive Secretary of the Secretary's Task Force on Alzheimer's Disease.

Again, it is a pleasure for me to welcome both of you. I would ask you to proceed in the order in which I introduced you.

STATEMENT OF DR. ROBERT B. HELMS, ASSISTANT SECRETARY FOR PLANNING AND EVALUATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY DR. GENE D. COHEN, DIRECTOR, PROGRAM ON AGING, NATIONAL INSTITUTE ON MENTAL HEALTH, AND EXECUTIVE SECRETARY, TASK FORCE ON ALZHEIMER'S DISEASE, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. HELMS. Thank you, Mr. Chairman and members of the committee.

I have already been introduced, and with me is Dr. Gene Cohen, as you said, who is the Executive Secretary of the Department's Task Force on Alzheimer's Disease. Let me add that Dr. Cohen also treats Alzheimer's patients and is therefore very familiar with this disease from a clinical perspective.

Secretary Bowen has asked me to provide you with an overview of the activities of our Department regarding the serious matter of care of people with Alzheimer's disease and other related dementias.

As a physician, Dr. Bowen has cared for many persons with this debilitating condition and understands the needs and concerns of patients and their families. As head of the Department of Health and Human Services, he has promised to give attention to the special needs of victims of Alzheimer's disease and the other health care needs of the elderly.

In addition to speaking today in my position as Assistant Secretary for Planning and Evaluation, I am also here in my role as a member of the Department's Task Force on Alzheimer's Disease. This task force was established early in 1983 and and is chaired by the Assistant Secretary of Health. Other members include the Surgeon General, the Commissioner on Aging, the Directors of the National Institute on Neurological and Communicative Disorders and Stroke, the National Institute of Mental Health, the National Insti-

tute on Aging, the National Institute of Allergy and Infectious Diseases, and representatives of the Health Care Financing Administration and the Veterans' Administration.

The task force has a mandate to coordinate the intensive ongoing research being done by the Federal Government on Alzheimer's disease, to create a mechanism for sharing information among the members, identify the most promising research avenues to explore, and translate that research into policy, programs, and practical means for improving the quality of life for persons with Alzheimer's disease.

Through this task force and several other coordinating bodies and functions, our Department believes that the mechanisms necessary to mobilize the efforts of the executive branch regarding research and services to persons with dementia are already in place. There have been a number of joint projects fostered between and among several members of the task force on such significant matters as diagnostic assessment tools and family care-giving.

Research on services for persons with dementia, which I know is of special interest to you, has ramifications far beyond health care. The needs of Alzheimer's victims, as well as persons with other chronically disabling conditions, involve a wide spectrum of Government agencies concerned with income, housing, and social service interests.

As a member of the Alzheimer's Disease Task Force, my office assisted in the preparation of two reports for the House Appropriations Committee in February 1985 and in May 1986, and I will be pleased to make those available. These describe HHS research activities regarding health and other services for the care of this population and the whole range of ongoing federally funded benefits which are available to many persons with this condition. These reports also state the Department's policy on care for persons with Alzheimer's disease. Essentially, this policy is threefold: First, sponsoring scientific efforts to better understand, treat and eventually cure and prevent this disorder; second, supporting demonstration, training, and community assistance projects to educate the public about this disease and to promote innovative methods of helping Alzheimer's victims and their families; and, third, assisting in the provision of medical and supportive services needed by Alzheimer's patients and their families in hospitals, nursing homes and in the community.

The first of these three activities requires a specific targeted approach to Alzheimer's disease accompanied by related work on basic biology, chemistry, and psychology of the aging brain.

The second also requires some targeting at the specific disease, although some of the training and demonstration activities sponsored by the Department address Alzheimer's disease within a broader framework of assistance to persons with functional disabilities, whether or not caused by Alzheimer's disease.

Because of the nature of Alzheimer's disease, the third area is largely the long-term care issue—how to provide continuing assistance to persons who can no longer care for themselves. The loss of the capacity for self-care not only affects Alzheimer's patients; there are also many other persons, most of whom are elderly, who suffer from chronic disease and disability. We believe that solutions

to the problems of long-term care must be sought within this broader context.

Let me give you an example of our approach to long-term care policy formulation. In cooperation with the Health Care Financing Administration and the Administration on Aging, my office was responsible for conducting the national long term care channeling demonstration.

This study, which was conducted at 10 sites in 10 different States was designed to test the extent to which a community-based long-term care system that combines case management, care planning, and the delivery of health and social services, is a cost-effective alternative to a medical-institutional model. Channeling did not set out to serve people with a particular medical diagnosis, but to meet the needs of people with very limited functional impairment levels living in a situation which could not provide adequate support from family and friends.

While we do not know with certainty how many of the more than 6,300 people in the sample actually had Alzheimer's, we estimate that a little over 30 percent had serious cognitive impairments.

We are beginning to do more research on this data. It is a very large data set, and we hope to have more information from the data as we go along. We also have some other data, things which are outlined in my testimony.

For the sake of saving time, let me skip to a word about a more recent activity which Secretary Bowen and the President have directed, which relates to Alzheimer's disease. That is the study of catastrophic illness.

By year-end, the Department is to report on how the private sector and Government can work together to address the problems of affordable insurance for those whose life savings would otherwise be threatened when a catastrophic illness strikes. The work groups involved in this effort will specifically examine the catastrophic financial burdens associated with long-term care, as well as private financing options which may help to alleviate some of these burdens.

Among the various alternatives to be examined are individual retirement account approaches, long-term care insurance, family caregiving incentives, continuing care retirement communities, home equity conversion, pension benefits, and social health maintenance organizations. The market potential for these options is being explored, including perceived barriers to their future development.

We are also carefully looking at the characteristics of persons who require long-term care services, including those with cognitive impairment caused by such conditions as Alzheimer's disease.

We appreciate the opportunity to review our activities, and Dr. Cohen and I would be pleased to respond to your questions.

[The prepared statement of Dr. Helms and responses to questions submitted by Senators Metzenbaum and Grassley follow:]

TESTIMONY

Robert B. Helms, Ph.D.
Assistant Secrtary for Planning and Evaluation

Department of Health and Human Services

HEARING

ON

CARE OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

July 22, 1986

Subcommittee on Aging

Senate Committee on Labor and Human Resources

Mr. Chairman and Members of the committee.

My name is Robert Helms and I am the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services. I am accompanied by Dr. Gene Cohen who is Director of the Program on Aging at the National Institute of Mental Health and Executive Secretary of the Department's Task Force on Alzheimer's Disease.

Secretary Otis Bowen has asked me to provide you with an overview of the activities of our Department regarding the serious matter of care of people with Alzheimer's disease and other related dementias. As a physician, Dr. Bowen has cared for many persons with this debilitating condition and understands the needs and concerns of patients and their families. As head of the Department of Health and Human Services, he has promised to give attention to the special needs of victims of Alzheimer's disease and other health care needs of the elderly.

In addition to speaking as the Assistant Secretary for Planning and Evaluation, I am also here in my role as a member of the Department's Task Force on Alzheimer's Disease. This task force was established early in 1983 and is chaired by the Assistant Secretary of Health. Other members include the Surgeon General; the Commissioner on Aging; the Directors of the National Institute on Neurological and Communicative Disorders and Stroke,

National Institute on Mental Health, National Institute on Aging, National Institute of Allergy and Infectious Diseases; and representatives of the Health Care Financing Administration and the Veterans' Administration.

The Task Force has a mandate to --

- o Coordinate the intensive on-going research being done in the Federal Government on Alzheimer's disease.

- o Create a mechanism for sharing information among the members of the task force.

- o Identify the most promising research avenues to explore.

- o Translate that research into policy, programs, and practical means for improving the quality of life for persons with Alzheimer's disease.

Through this Task Force and several other coordinating bodies and functions, our Department believes the mechanisms necessary to mobilize the efforts of the Executive Branch regarding research and services to persons with dementia are already in place. There have been a number of joint projects fostered between and among several members of the Task Force on such significant matters as diagnostic assessment tools and family caregiving. Research on services for persons with dementia, which I know is

of special interest to you, has ramifications far beyond health care. The needs of Alzheimer's victims, as well as persons with other chronically disabling conditions, involve a wide spectrum of government agencies concerned with income, housing and social service interests.

As a member of this Task Force, my office has assisted in the preparation of two reports for the House Appropriations Committee in February 1985 and May 1986 (which we shall be pleased to make available to the Subcommittee) which describe DHHS research activities regarding health and other services for the care of this population and the whole range of ongoing Federally-funded benefits which are available to many persons with this condition.

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1) Sponsoring scientific efforts to better understand, treat and eventually cure and prevent this disorder;

2) Supporting demonstration, training and community assistance projects to educate the public about this disease and to promote innovative methods of helping Alzheimer's victims and their families.

- Assisting in the provision of medical and supportive services needed by Alzheimer's patients and their families -- in hospitals, nursing homes and in the community.

The first of these three activities requires a specific targeted approach to Alzheimer's disease, accompanied by related work on basic biology, chemistry and physiology of the aging brain. The second also requires some targeting on the specific disease, although some of the training and demonstration activities sponsored by the Department address Alzheimer's within a broader framework of assistance to persons with functional disabilities, whether or not caused by Alzheimer's disease.

Because of the nature of Alzheimer's disease, the third area is largely a long-term care issue: how to provide continuing assistance to persons who can no longer care for themselves. The loss of the capacity for self-care not only affects Alzheimer's patients. There are also many other persons, most of whom are elderly, who suffer from chronic disease and disability. We believe that solutions to the problems of long-term care must be sought within this broader context.

Let me give you an example of our approach to long-term care policy formulation. In cooperation with the Health Care Financing Administration and the Administration on Aging, my office was responsible for conducting the National Long-Term Care

Channeling Demonstration. This study, which was conducted in ten sites in ten different States, was designed to test the extent to which a community-based long-term care system that combines case management, care planning and the delivery of health and social services is a cost-effective alternative to a medical/ institutional model. Channeling did not set out to serve people with any particular medical diagnosis but to meet the needs of people with very limited functional impairment levels living in a situation which could not provide adequate support from family and friends.

While we do not know with absolute certainly how many of the more than sixty-three hundred people who comprised the sample for the Channeling demonstration had a firm diagnosis of Alzheimer's disease, we estimate that 30.4% had serious cognitive impairments. With a research effort as extensive as Channeling, you can understand that we are only beginning to mine the vast wealth of data that have been collected and which can tell us a great deal about how to improve care for subpopulations such as those with patterns and types of impairment similar to those found in dementia.

In addition to the Channeling data, major new sources of longitudinal long-term care data are the 1982 and 1984 National Long-Term Care Surveys including the Survey of Informal Caregivers. These surveys are detailed interview studies of the

65 and over population who are living in the community and experience chronic impairments. To give you an idea of its scope, approximately 6,400 impaired older persons were selected for detailed interviews out of an initial screen of over 36,000 Medicare enrollees. A number of analyses have already been carried out using these new data sources inside and outside the Federal Government.

I share the interest of the members of the committee on the needs of caregivers of persons with dementia. The reports on Alzheimer's disease, which I described earlier, provide descriptions of some of the major efforts being sponsored by different agencies within our Department. Some of these projects are specifically for caregivers of persons with Alzheimer's disease. Others assist families with members having dementia as well as many other impairing conditions.

Under the auspices of the Office of Human Development Services, a Family Caregiving Project was recently established as a means of coordinating research and demonstration projects of six DHHS offices which provide funding for innovative approaches to assisting family caregivers. As part of this project, a successful conference was recently held which brought together grantees, Federal staff and various advocacy and professional groups interested in assisting family caregivers.

Finally, I would like to briefly describe an activity which Secretary Bowen has undertaken at the direction of the President which has significance for persons with Alzheimer's disease and other catastrophic illnesses. By year-end, the Department is to report on how the private sector and government can work together to address the problems of affordable insurance for those whose life savings would otherwise be threatened when a catastrophic illness strikes.

The work groups involved in this effort will be specifically examining the catastrophic financial burdens associated with long-term care as well as private financing options which may help to alleviate some of these burdens. Among the various alternatives being examined are individual retirement account approaches, long-term care insurance, family caregiving incentives, continuing care retirement communities, home equity conversion, pension benefits and social health maintenance organizations. The market potential of these options is being explored including perceived barriers to their future development. We are also carefully looking at the characteristics of persons who require long-term care services including those with cognitive impairment caused by such conditions as Alzheimer's disease.

I appreciate the opportunity to present this overview of our activities. Dr. Cohen and I would be pleased to respond to any of your questions.

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FOLLOW-UP TO JULY 22, 1986 HEARING ON ALZHEIMER'S DISEASE

Senator Metzenbaum Question:

Standardized Evaluation As I understand it, there are and have been several demonstration programs for home and community-based care. Are there standardized ways for evaluating such programs?

Dr. Helms Reply:

Evaluation must be tailored to the specific questions and populations of individual research and demonstration projects. Wherever possible, standard instruments are used so that comparisons might be drawn between and among as well as within areas of inquiry. Two recent major studies of home and community-based care, the National Long-Term Care Channeling Demonstration and the Evaluation of Coordinated Community-Oriented Long-Term Care Demonstration Projects conducted by Berkeley Planning Associates, used similar study instruments.

Senator Metzenbaum Question:

Disseminating Information How is the information you generate disseminated?

Dr. Helms Reply:

Within my office is the Policy Information Center (PIC) which provides a centralized source of findings from evaluative research relevant to the Department's programs and policies. Ongoing and completed HHS evaluations are tracked, compiled and retrieved. PIC makes the following services available to HHS employees as well as to any interested party: Library of Evaluative Research Studies, Compendium of HHS Evaluations and Other Relevant Studies, Quarterly Memorandum and an On-Line Database System. Study results are placed in the National Technical Information Service (NTIS) as well as several other widely used dissemination systems. Certain studies are issued as Department publications available through the Government Printing Office. In addition, DHHS contractors, grantees and ASPE employees frequently communicate findings through professional journals and conferences. In addition, public use data tapes are available on studies and surveys such as the National Long-Term Care Channeling Demonstration and the National Long-Term Care Survey.

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Senator Metzenbaum Question:

Assessment Do nursing homes have, upon admission, adequate assessments of the functional abilities of a patient with Alzheimer's, and is there a plan for maintaining these abilities as long as possible?

Do nursing homes need a standardized assessment instrument? And training on how to manage patients with functional limitations? How do you recommend improving the situation?

Dr. Helms Reply:

If a person's placement in a nursing home is being underwritten by Medicare, a three-day hospital stay would have preceded the admission. It would be expected that the attending physician would have arranged for any necessary diagnostic work-up while the person was still in the hospital and used the resultant data in certifying the need for care under Medicare. Following admission, the nursing home is required as part of the "Conditions of Participation" for Medicare to develop and maintain a written patient care plan consonant with the attending physician's plan of medical care (405.1124(d)). The plan indicates care to be given and goals to be accomplished and which professional service is responsible for each element of care. Consequently, assessment of functional abilities is normally undertaken to properly complete the planned treatment. The patient care plan is reviewed, evaluated, and updated as necessary by all professional personnel involved.

As to efforts to maintain functional abilities, Medicare requires the facility to have an active program of rehabilitative nursing care which is an integral part of nursing service and is directed toward assisting each patient to achieve and maintain an optimal level of self-care and independence (405.1124(e)). In addition, the medically related social and emotional needs of the patient are to be identified and services provided to meet these needs (405.1130(a)).

The same conditions regarding assessment and care planning also apply to Medicaid patients in skilled nursing facilities. Beyond these requirements, States are free to develop their own policies regarding Medicaid. For instance, some States such as Virginia have initiated a pre-admission process for all persons who are or might soon be eligible for Medicaid which includes an assessment of functional abilities.

The Department has underway a response to a nursing home study conducted by the Institute of Medicine (IOM) which will be addressing improvements in present requirements dealing with assessment and care planning. The Health Care Financing Administration contracted with the IOM in 1982 to study nursing

home regulatory and enforcement issues and to provide recommendations for improving the quality of life of residents.

There are a number of Federally-sponsored research and demonstration projects which involve experimentation with instruments which assess functional impairment. The Health Care Financing Administration recently added a component for assessing mental status in several projects which are addressing quality assurance in nursing homes. Technical assistance with this component has been provided by the staff of the dementia project at the Congressional Office of Technology Assessment.

Over the years, there have been attempts to develop a national standardized assessment instrument. However, because of the wide range of conditions and circumstances to be found in patients and nursing home facilities, it has not been possible to develop something that was reliable, manageable and cost-effective.

As to instruments which can specifically determine the existence of Alzheimer's disease or some other form of dementia, the state of the art does not indicate that we are near a time when a standardized assessment instrument can or should be promulgated.

The Department has promoted training on how to work with patients with functional limitations through a number of different projects. Some of the efforts which focus on persons with mental impairments are described in the reports which accompanied our testimony. The projects include: the Mental Health in Nursing Homes project, the Teaching Nursing Home program, Alzheimer's Disease Research Centers and the New York State Mental Impairment Training in Nursing Homes program. Department agencies which incorporate training concerns for the care of the functionally impaired in many of their ongoing programs include the Administration on Aging, the National Institute of Mental Health, the Health Resources and Services Administration and the National Institute on Aging.

The preceding material summarizes Federal activities regarding nursing home practices relevant to assessment and care planning. There are many other practices, initiated by other levels of government, the nursing home itself, trade associations, scientific groups, professional membership organizations and private foundations which impact on the nature and quality of care in these facilities.

Senator Grassley Question:

Dr. Helms, you noted that research on services for persons with dementia has ramifications far beyond health care. I think I get your point here; but would you also say it has ramifications beyond care specifically for people with Alzheimer's disease or some other dementia?

That is, are there long-term care needs of people with Alzheimer's disease generically different than the long-term care needs of other people with chronic disabilities or functional limitations?

Dr. Helms Reply:

It is difficult to identify uniquely generic long-term care differences between Alzheimer's disease and the many other diseases and conditions which can result in some of the same physiological, psychological and social manifestations and needs as this form of dementia. It might be said that one of the distinctive characteristics of Alzheimer's disease is its worsening progression, often over a very long period of time. But even that situation can result from several other diseases.

Senator Grassley Question:

Many of us in the Congress are very interested in the Secretary's Task Force on Catastrophic Health Care expenses. What is the role of your office in that task force, and, to your knowledge, will the task force include consideration of Alzheimer's disease and other dementias?

Dr. Helms Reply:

There are three working groups within the Department looking at three areas of concern: catastrophic health expenses in the general population, among the elderly and the private financing of long-term care. My office is taking the lead for the examination of catastrophic health expenses in the general population. We have substantial staff representation on the other two task forces.

Because we must include consideration of all chronic illnesses, we are focusing on generic aspects of conditions such as Alzheimer's disease.

Senator GRASSLEY. Dr. Cohen, do you have a statement?

Dr. COHEN. No, Senator, I do not.

Senator GRASSLEY. I do have some questions, then.

To start off with, Dr. Helms, when Secretary Heckler was the Secretary, she made Alzheimer's disease one of her highest priorities and created a Secretary's Task Force on Alzheimer's Disease as one indication of that interest.

Now I know that the Secretary's task force is still existing and working, and that Dr. Cohen is there to help keep it on track. So let me ask this question. Are you able to place the Alzheimer's effort among Secretary Bowen's top priorities, and if so, how high of a priority is it within the Department now?

Dr. HELMS. Well, given the Secretary's personal interest in this, let me say that when he came in, he reviewed all of the existing task forces, special committees, and efforts, and that kind of thing. Knowing that he had to put emphasis on those that were among his highest priority, he elected to keep the Alzheimer's task force in place at the Secretarial level—meaning, chaired by the Assistant Secretary of Health and with participation by the major components of the Office of the Secretary.

So I do know that his personal interest in this is very great, and particularly in this area of financing of catastrophic care, we are trying to get at the broader policy as it relates to Alzheimer's disease. Dr. Bowen is very interested in Alzheimer's disease, and I think it is a very high commitment and priority of his.

Senator GRASSLEY. OK. You noted, Dr. Helms, that some 30 percent of the channeling demonstration caseload had serious cognitive impairments. One of the points which was made very forcefully in a workshop that this subcommittee sponsored on services-related research on Alzheimer's disease was that there are numerous data bases generated by given agencies that contain data on dementia victims which is yet to be utilized.

First, I presume that your remarks about the channeling demonstration mean that you will be continuing to analyze the data specifically with respect to dementia victims—is that fair to assume?

Dr. HELMS. Yes. As a matter of fact, this data is about to become available on a public use tape, and we plan to make efforts to notify interested researchers about the availability of this very large and, I think, interesting data set.

Senator GRASSLEY. It is going to be made available—would that be——

Dr. HELMS. Also, my staffs are committed to continuing studying this, too.

Senator GRASSLEY. OK. How about a secondary analysis for what they might tell us about dementia victims?

Dr. HELMS. As I say, it is difficult—we have the same problems, I think, in the data set as was mentioned earlier about the problems with diagnosing Alzheimer's. We will try to do it the best we can. I cannot at this point say to what extent we can actually define those people that have Alzheimer's. But we certainly intend to study that general area to the best we can.

Senator GRASSLEY. Dr. Cohen, some people criticize an activity like the Secretary's task force as being basically unable to contribute very effectively to the Department's Alzheimer's research

effort because the participants are too concerned with protecting their own bureaucratic turf—and of course, we know that is a disease of the Federal Government generally, and that therefore such high-level committees will never be able to set clear, innovative direction. Coordination and direction-setting in the Alzheimer's research effort is clearly of great importance, and some of the bills before this subcommittee deal in one way or another with that coordination issue.

In light of this, would you comment on the criticism I have just stated and where we are headed if there is some legitimacy to the criticism?

Dr. COHEN. I assumed that dealing with the complexity of multiagency involvement would be part of the challenge I would confront in carrying out my responsibilities as executive secretary for the task force.

The other side of this situation, though, is that the Government has been very fortunate to have many talented partners in the research effort on Alzheimer's disease—partners from both within the Department of Health and Human Services and the Veterans' Administration. It is part of the nature of a problem like Alzheimer's disease that, when you do not know its cause, you have to plant a number of seeds (to involve a number of different programs), exploring many different directions in seeking to better understand the disorder. That is part of the phenomenology of inquiry in such areas. It requires and we benefit from a multipartnered effort.

In that thrust, I think that the members of the Secretary's task force on Alzheimer disease have responded quite well and admirably in terms of the exchange of information, this being well-reflected in the task force's report that was published in 1984. That Report had very wide dissemination, reviewed in detail the different activities of the Department, and has resulted in a significant number of formal and informal mechanisms for sharing of information since its release.

A very interesting activity that took place a year ago, jointly sponsored by the task force and the Alzheimer's Disease and Related Disorders Association, provides a good example; a national conference was held which in effect created a national forum for a dialogue between family members and the heads of the different agencies focused on Alzheimer's disease. The purpose of the conference was not only to share information, but to share questions as well on the next steps to take in addressing Alzheimer's disease. This dialogue has been only one of many among a range of sources of structured feedback from both families and the field that the task force has tried to incorporate in its efforts.

Therefore, I think that whereas one always confronts challenges in coordinating the input of multiple participants in a complex task, one typically finds that the whole effort by virture of its complexity has required and benefitted from that mix of expertise and collaboration.

Moreover, since the task force's initial report, there have been other reports, two of which Dr. Helms has mentioned. In addition, most recently, the task force's latest effort has produced a working notebook that has just been distributed to the task force members,

containing a comprehensive update of Alzheimer's disease related activities that are going on throughout the Department of Health and Human Services and the Veterans' Administration. This notebook is designed to allow the easy addition of regular updates,thereby greatly facilitating the coordination process in the rapid sharing of new information. As a final point, it should be noted that the original plan was to have this notebook by September, but the exchange of information was so effective, it was ready 4 months early; I believe that this is an excellent reflection of the cooperative spirit and cohesiveness of the participating agencies on the task force, reflecting further the efficiency of the task force's coordinated role.

[Response of Dr. Cohen to question submitted by Senator Grassley and additional statement supplied for the record follow:]

DEPARTMENT OF HEALTH & HUMAN SERVICES — Public Health Service

Memorandum

Date August 7, 1986

From Executive Secretary, Department of Health and Human Services Task Force on Alzheimer's Disease

Subject Response to Additional Question from Senator Grassley's Hearing on Alzheimer's Disease

To Penny Bogas

I am responding to the additional question sent to me from Senator Grassley's recent Hearing on Alzheimer's Disease.

QUESTION:

"I think most of us are familiar with the first, 1984, Report of the Task Force. Perhaps you could give us a brief update on the activities of the Task Force since then?"

RESPONSE:

Since the Department of Health and Human Services (DHHS) Task Force Report on Alzheimer's Disease was prepared, the Task Force has continued to actively carry out its research coordination and information sharing responsibilities. In addition to routine exchanges of information and collaboration in ongoing efforts that regularly take place within the Task Force's network, some further examples of the Task Force's work are briefly discussed as follows:

The 1984 Task Force Report contained an Appendix which delineated the portfolio of activities relevant to Alzheimer's disease carried out by DHHS and the VA as of the fall of 1983. In May 1986 a new report, in the form of a working notebook, was developed by and for the members of the Task Force. The 1986 Report updates the earlier portfolios, while describing highlights of research results and other relevant activities on Alzheimer's disease; it also provides useful detailed lists of projects, investigators, and sites of the respective studies in progress. The notebook was designed to allow the easy addition of regular updates, thereby further facilitating the coordination and information sharing processes of the Task Force.

.....Two reports for the House Appropriations Committee (one in February 1985, the other in May 1986) were coordinated through the Task Force; these described a number of research and services related activities that the Department has been involved with in the area of Alzheimer's disease.

.....A major National Conference on Alzheimer's Disease, focused on families and co-sponsored by the Task Force and the Alzheimer's Disease and Related Disorders Association (ADRDA), took place in May 1985. Representatives from local chapters of ADRDA from all over the country participated in this important meeting. Leading scientists from the field were also participants in this conference. The conference created a national forum for a dialogue between family members and heads of the different Federal agencies focused on Alzheimer's disease. The purpose of the conference was not only to share information from the results of research, but to share ideas as well on the next steps to take in initiatives on Alzheimer's disease.

.....A Workgroup of the Task Force published a consensus report on general guidelines for approaching the diagnosis of Alzheimer's disease. Additional Workgroups on other highly targeted areas relevant to Alzheimer's disease are presently being considered.

Gene D. Cohen, M.D., Ph.D.

AAHA

STATEMENT

by the

AMERICAN ASSOCIATION OF HOMES FOR THE

AGING

on

THE CARE OF PEOPLE WITH ALZHEIMER'S
DISEASE AND RELATED DEMENTIAS

for the

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON LABOR AND HUMAN RELATIONS

U.S. SENATE

August 19, 1986

AMERICAN ASSOCIATION OF HOMES FOR THE AGING
1129 20th Street, NW, Suite 400, Washington, DC 20036 202 · 296 · 5960

Mr. Chairman and members of the Subcommittee, the American Association of Homes for the Aging appreciates the opportunity to submit testimony outlining the ever-increasing need for concerted and cooperative action on behalf of the victims of Alzheimer's Disease. AAHA commends the Subcommittee for its continued efforts and diligence in securing the necessary funds and accompanying supportive services required by Alzheimer's patients and their families.

AAHA is a national non-profit organization representing almost 3000 nonprofit facilities which provide housing, health care, long term care, and community services daily to more than 500,000 elderly individuals throughout the United States. Over 75% of AAHA members are affiliated with religious organizations. The remaining members are sponsored by private foundations, government agencies, unions, fraternal organizations, and community groups.

Many of AAHA's member facilities have developed specialized Alzheimer's programs including adult day care, long term and respite care, and the facilitation of family support group meetings, in order to respond to the service needs of the victims of Alzheimer's Disease and their families.

AAHA Member Activities

The Adult Day Health Services of the Handmaker Jewish Geriatric Center, Tuscon, Arizona, has developed a comprehensive program of services for persons being cared for at home, offering respite and a supportive environment to caregivers and patients. The full program includes health surveillance, speech, occupational and music therapy, individual and group counseling, training in activities of daily living, educational, recreational, and leisure activities as well as nutritional guidance and a hot noon meal. Adult Day Health Services currently serves more than 500 people out of two centers including a protective care unit which specifically addresses the needs of Alzheimer's and related disorders participants. In addition to the full gamut of day health activities, the protective care unit offers activities such as reality games which include the identification of objects, sounds, smells, and tastes, and the recollection of names, places, and past events. These activities concentrate on and encourage maintenance of individual abilities, while, at the same time, recognize individual limitations.

The Morningside House Nursing Home Company, Inc., Bronx, N.Y., is a 386-bed facility which includes two in-house units focused primarily on the care of residents with Alzheimer's Disease. Morningside House has responded to the broad range in functioning levels of patients suffering from Alzheimer's Disease and related disorders through development and implementation of a Comprehensive Mental Health Treatment Program. The program incorporates a seven-branch system of therapy including family support groups, group therapy with the severely impaired, physical exercise in a variety of forms; and, for higher functioning patients, reminiscence therapy which involves life recollection up to, and including, admission to the nursing home. The program also consists of skills training which stresses compensation for skills lost; orientation which incorporates a "buddy system" for mild to moderately impaired residents; and support therapy groups conducted on levels which respond to patients' specific needs and functioning, such as difficulty or inability to

articulate. Morningside House has also implemented environmental and dietary modifications, such as inclusion of more finger foods and specially designed eating utensils, which enhance and encourage optimal functioning for Alzheimer's patients in this fundamental activity of daily life.

The above descriptions respresent only two examples of the many excellent and innovative programs which have been initiated within the voluntary sector and which need public support in order to continue to benefit the rising number of Alzheimer's victims and their families.

Needed Federal Legislation

The American Association of Homes for the Aging, as a representative for both institutional and non-institutional providers of care for the elderly, would like to take this opportunity to express its support for S. 1736, the Comprehensive Alzheimer's Assistance Research and Education Act of 1985 (CARE) and S. 1835 and S. 2183, the Alzheimer's Disease Demonstration, Research and Assistance Acts of 1985 & 1986. AAHA is also supportive of many of the concepts embodied in S. 174, the Alzheimer's Disease and Related Disorders Treatment Act of 1985. These bills all contain components which respond to the needs of Alzheimer's victims and their families by seeking to provide increased funds and avenues for the advancement of research and the coordination of programs and services, and establish cooperative efforts between the states and Federal Government to develop services and policies.

AAHA particularly commends the Subcommittee's efforts to examine the roles of Medicare and Medicaid in covering nursing home care, respite, and home health care. The cost of caring for victims of Alzheimer's Disease in terms of both investment of time and real dollars increases steadily as the degenerative progression of the disease advances. The often occurs over a period of 7-12 years. The increasing need for constant supervision and surveillance, due to accelerating episodes of inappropriate, unpredictable, or possibly dangerous behaviors, places a heavy burden on the family caregiver. Frequently, these caregivers are spouses, who are elderly themselves. As the disease advances, there is an accompanying progression in the demand for health and health related services. A pilot study recently cited in "Gerontologist" estimated the costs involved in home care for an elderly person suffering from Senile Dementia, to be approximately $11,735 per year. AAHA advocates implementation of the Medicare and Medicaid demonstration projects as contained in both the CARE bill and in S. 1835 as an avenue toward the expansion of the Medicare and Medicaid programs to include coverage for services designed to allow maintenance of the patient at home for as long as possible. The Association urges recognition of the opportunity to begin to bring these projects to actuality by supporting the Alzheimer's Medicare Demonstration Projects provision included in the House Energy & Commerce FY'87 Budget Reconciliation legislation.

While AAHA strongly supports the expansion of coverage for services under the Medicare and Medicaid programs for Alzheimer's patients, the Association does believe that it would be short-sighted to limit reimbursement for these services to centralized treatment centers. As has been previously stated, many AAHA members, as well as others within the voluntary sector, have already sought to establish highly developed programs for the victims of Alzheimer's Disease and their families. Expanded coverage for services should be available

to these providers who have already assumed the initiative to develop programs, to allow for the continued enhancement of existing services, and to provide incentive for the introduction of new programs and initiatives.

AAHA also recognizes that almost all Alzheimer's victims will require nursing home placement at some point, even with the availability of home support services, due to the absence of family caregivers or when care needs extend beyond the family caregiver's capacities. However, Medicaid and Medicare reimbursement for nursing home care, whether based on a case mix system or on ICF/SNF level of care distinction, is particularly inadequate for Alzheimer's patients as they tend to demonstrate deceptively low care level needs. Due to the high degree of involvement required by staff in direct care behaviors with these patients, caring for Alzheimer's patients is labor intensive and thus costly, even where the need for skilled services is low.

Current Medicare policy often precludes coverage for victims of Alzheimer's Disease because skilled services may not be required and there exists limited "rehabilitative" potential in the acute care sense. This represents to AAHA a dramatic example of the need for better understanding of the concept of rehabilitation in the context of long term care. For Alzheimer's victims and other chronically impaired elderly, rehabilitation should mean using therapies directed toward maintaining existing functioning levels or compensating for skills lost. Successful "rehabilitation" is to enhance both independence and individual dignity for as long as possible, as this is integral to providing optimal quality of care and consequently, ensuring optimal quality of life. While current Medicaid policy does provide nursing home coverage for poor elderly, reimbursement also proves to be inadequate due to the nature of the care needs of Alzheimer's patients as described above.

AAHA supports a review and modification of public reimbursement and regulatory policies and procedures to accommodate the need for respite care. Again, for caregivers whose capacities have been over extended the availability of respite care can provide a period of relief which, in conjunction with other community support systems, will ultimately allow the patient to remain at home for a longer period of time. Respite care may also provide an avenue for ensuring optimal quality of care while Alzheimer's victims awaiting long term placement in a nursing home. Other benefits afforded through the use of respite care are the opportunities to evaluate both the patient's and the family's response to placement, a tool now unavailable to providers in anticipating the therapies and support services which will prove beneficial at the point nursing home care is required.

Public Education

Educating the public about Alzheimer's Disease and providing assistance in accessing information and services to families of Alzheimer's victims, components contained in both CARE's National Education Program and in S.2183's provisions for the collection and dissemination of information by the Department of Health and Human Services (HHS), are also areas supported strongly by AAHA. The Association has heard repeatedly through its members that the most critical problem facing families of Alzheimer's patients is the difficulty in accessing information. Information needs to be made available on issues such as the nature of the disease, research findings, public and private insurance programs, service options, and how to find a physician or medical

center that provides access to comprehensive diagnosis and assessment. AAHA commends the effort to establish a Central Information Clearinghouse as well as the direction to area agencies on aging to maintain registries for various medical and community services. The Association suggests further that an accompanying implementation of a toll-free hotline would enhance the use of both of these entities as referral resources to health care providers and the general public.

AAHA also continues to recognize the need to disseminate information to our members, as well as to the community. In 1984, the Association called for the development of an Alzheimer's Network to provide a central vehicle for the sharing of information and resources. The Network, comprised of nearly 100 representatives of AAHA member facilities, views 1986 as a planning year for the facilitation of activities leading to goals which include the compilation of an AAHA resource directory listing both institutional and non-institutional programs serving Alzheimer's victims and their families. Also, to address concerns expressed by AAHA members, proposed network activities include the provision of technical assistance to members in their respective states in developing Alzheimer's programs and services, the facilitation of support groups serving families and/or professional caregivers, the facilitation of advocacy groups to represent Alzheimer's victims and their families before state legislatures, and assistance in the development of a hotline, viewed as integral to the dissemination of specific resource information on a state level.

Most recently, AAHA appointed a Member Task Force on Alzheimer's Disease to work with the Association in determining how it can best serve the needs of members and facilities caring for Alzheimer's patients. This Task Force will work to chart a course for Alzheimer's activities by the Association in 1986 and future years. The Task Force has identified as a priority the care of Alzheimer's victims in nursing homes and communities for older Americans, emphasizing AAHA's commitment to the provision of the highest quality of care for these individuals. AAHA's Task Force would welcome the opportunity to meet with the Committee at any time for further discussion of these issues.

Continued Federal Support

Federal support for geriatric training in medical schools, with career teacher incentives as well as research incentives, is one aspect of the need for continued and more specialized education that AAHA views as integral to the diagnosis, treatment, and management of Alzheimer's Disease and related disorders. Joint Federal and state efforts to provide ongoing educational and training services for the broad range of health and long term care professionals involved in the provision of services to Alzheimer's patients and their families is also critical to the treatment and accurate dissemination of clinical information.

The commitment to the advancement of research into the cause, prevention, and treatment of Alzheimer's Disease and related disorders, as evidenced in both S. 1736 and S. 2183, through extension of the current Research Center Program is commended by AAHA. The Association is aware of the effects that funding cuts and deficit reduction actions have had, and can have, on the maintenance and expansion of this program. We do feel, however, that is is important for Congress to demonstrate its recognition of Alzheimer's Disease as a priority

issue, and to support the 2.5 million Americans currently suffering from this disease, by assuring no further reductions in the commitment levels sustained for the previous year.

S.2183 further requires the promulgation of regulations which would encourage medical examiners, coroners, and pathologists to provide reports concerning the findings of autopsies in which Alzheimer's disease was a contributing factor. AAHA supports this type of collection and analysis of epidemiological data as being essential to the enhancement and development of diagnostic tools and treatment protocols. The study of the incidence, prevalence, patterns, and mechanisms of Alzheimer's may provide data which enables the identification and isolation of causes as well as the development of a more accurate picture of the natural progression of the disease.

AAHA believes that voluntary agencies play a vital role in the initiation and provision of services to the elderly, the victims of Alzheimer's Disease and related disorders. We also believe, however, that the Federal Government has a key role to play in responding to the needs of the aging in our society. We appreciate the Subcommittee's interest in this issue and pledge to work with you to develop programs and the necessary funding for these Alzheimer's initiatives.

Senator GRASSLEY. Well, thank you very much, and in closing, I would only say that your testimony and that of the other two panels is just part of an ongoing effort of this subcommittee to bring further attention as well as, hopefully, changed legislation and improved legislation on the general subject of an issue that still not enough is known about.

As an administrative matter, I would say to this panel as well as all the other panels that if you get questions in writing not only from those three Senators who were here, but also other Senators on the subcommittee that maybe could not be here and still might want to ask questions of you, we would ask that those would be returned in 15 days, and you would also have that period of time for the addition of any material that you might want to include or correct in the material already given.

With that statement, I declare the meeting adjourned.

[Whereupon, at 11:40 a.m., the subcommittee was adjourned.]

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